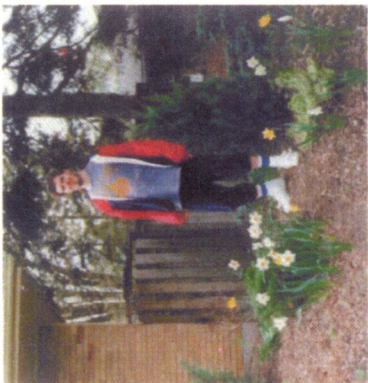
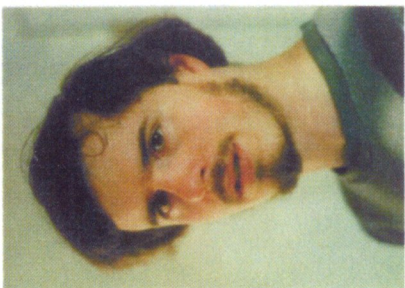
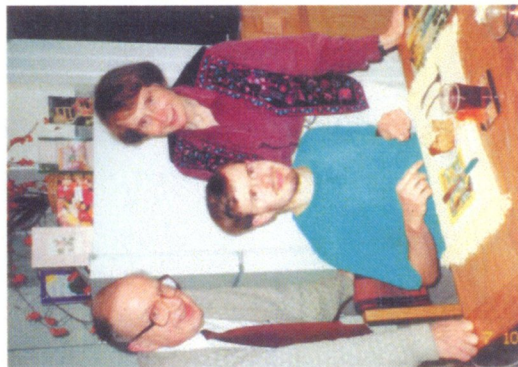
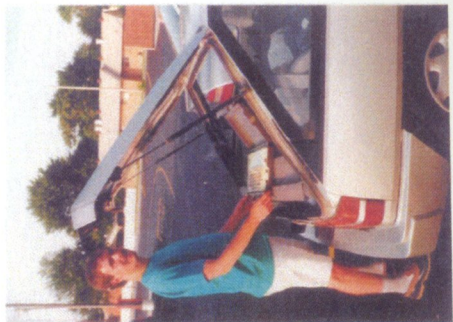


About myself:

Portrait of Andrew who has Autism



**Lucie Milne
with the Bloomfield Family**



About myself: portrait of Andrew who has Autism

By Lucie Milne with the Bloomfield family, Guelph, 1998. Reprinted 2003

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Photographs

The Bloomfields thank Lucie Milne for preparing *About myself* for publication, and Marie Puddister for scanning and arranging the photographs.

About myself was published to honour Victoria's commitment to her twin and to celebrate Andrew's new life in the community.

We hope readers will feel moved to be friends with adults with autism or others who are vulnerable.

A tax-creditable donation to Guelph Services for the Autistic will help to realize further person-centred life plans.

Guelph Services for the Autistic
A non-profit charitable corporation
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GUELPH, ON, N1E 1C9

About myself: portrait of Andrew who has autism

By Lucie Milne with the Bloomfield family, Guelph, 1998 (reprinted 2003)

A study of living with autism for 30 years. Themes range from diagnosis of classic autism in the young child and long-distance travelling over many years to reach services to the benefits of pet therapy, facilitated communicating and the discovery of hypersensitivity to drugs and some common foodstuffs. The story is poignant because Andrew's twin, who was his best friend and "window to the community," was killed in a winter traffic accident in February 1996.

Victoria began this book shortly before her death, to help Andrew to understand his life. It has been completed with the help of Lucie Milne, writer and retired Presbyterian minister, who got to know the Bloomfields when she and her husband Bill were at Knox Presbyterian in Guelph.

Stages of Andrew's life are surveyed in the early chapters. More than half the book is concerned with elements of his person-centred plan for living in the community and how this has been realized since 1996. Andrew explains these as "a home of my own with space and quiet," "regular structure with real work, learning and exercise," "friends who understand and believe in me," and "help with communication so people know I am smart." His goal in life is to "try best to be a good man." In supporting Andrew to implement his plan, his parents and friends have exercised faith, imagination and patience. At every stage, they ask themselves the question: "Is it good for Andrew?" and have developed innovative ways of supporting Andrew to answer that question himself.

The development of Andrew's intellectual potential and his practical skills on the computer illustrate the fact that, regardless of age or handicap, the human being is capable of growing, changing and creating. Andrew has said that having autism is like being a horse locked in a barn but desiring to be out in the field where it can run and be free. Andrew knows he is autistic, but he has the curiosity and desire to learn and to explore the world around and beyond him. Victoria opened those first windows for him. His family, his friends and his home continue to support his new life with all its dreams and plans.

This portrait of Andrew's life will interest and help others who are concerned to develop and realize person-centred plans, with the associated elements of self-determination and supported decision-making, individualized funding, personal relationships, sensitive management, partnerships and community development.

PART ONE

INTRODUCTION

It is not growing like a tree
 In bulk, doth make one better be;
 Or standing long an oak, three hundred year,
 To fall a log at last, dry, bald and sere.
 A lily of a day,
 Is fairer far in May,
 Altho' it fall and die that night;
 It was the plant and flow'r of light.
 In small proportions we just beauties see;
 And in short measures, life may perfect be.
 Ben Jonson - 17th century.

*ANNE VICTORIA BLOOMFIELD,
 died 11 February 1996 at the age of 27,
 following a car accident near Alma, Ontario.
 Victoria earned a BA Honours degree at the
 University of Guelph in 1990 and an
 MA degree in geography at McMaster in 1992.
 Her PhD degree was awarded posthumously at
 McMaster's Fall Convocation in 1996.*

Vickie died in a winter traffic accident as she was on her way home from driving her brother Andrew back to Midwestern Regional Centre after his usual weekend with his family in Guelph. Vickie's life, like the flower in Ben Jonson's poem, was cut short, yet the time of her blooming was extraordinarily full. It was a life she filled with love and involvement in opening the world to her twin, Andrew. Andrew has autism. In the last years of her life Vickie, in Andrew's words, became his window to the community.

VICKIE HURT
 TOO MUCH SNOW
 HURT HURT
 GRIEVE
 VICKIE LOVE
 NO MORE
 MUMMY LOVES
 ANDREW BLOOMFIELD LOVES VICKIE

KILL KILLED ROADS
 DEVASTATED
 HELP ME
 DADDY LOVES ANDREW BLOOMFIELD
 MORE HURT
 TOO DIFFICULT
 MORE SAD
 MUMMY GOT TO KEEP GOING
 LOVE VICKIE YES MUCH LOVE
 DEAD
 HAD BAD DREAM
 ANDREW BLOOMFIELD KNEW AHEAD YES
 GOOD MEMORY OF VICKIE
 GOOD SISTER
 LOVED VICKIE
 JUST SAD YES
 <Vickie was my> WINDOW TO THE COMMUNITY YES
 The message above was typed by Andrew using Facilitated Communicating
 after receiving news of his sister's death

Vickie began this book shortly before her untimely death, to help Andrew understand his life. Now the "scenes that took place through the window" must be recorded. *About Myself* is the story of Andrew, the story of a brother's life and of living with autism. As Andrew, without his best friend, moves into a new phase of his life, he builds on the experiences and opportunities that Vickie, and their parents and good friends have given him. However, we must not get ahead of the story, but instead start where the lives of Andrew and Vickie began, in New Zealand.

1 **EARLY YEARS**

The government store and a few traders' tents situated on a narrow isthmus in 1840 developed into the largest city and seaport in New Zealand. Here in Auckland on 6 May 1968, Andrew John was born, arriving ten minutes before his sister Anne Victoria.

The babies were in a hurry to enter the world for they were about five weeks premature. Twelve days before, birth "pangs" prompted the doctor to order an x-ray. TWO Babies! It was a surprise to both doctor and parents Elizabeth and Gerald.

Elizabeth, elder daughter of Methodist missionaries Stanley and Phyllis Andrews, was born and lived to age 12 in the Fiji Islands of the South Pacific. She attended secondary school and university in New Zealand. At the University of Auckland, Elizabeth became a junior lecturer in early 1965 and began to work part-time towards her doctorate over the following three years. It was at the university that Elizabeth met Gerald Bloomfield.

Born in Leeds, England and having earned a doctorate from the University of Nottingham, Gerry was appointed to the University of Auckland in 1964. An industrial geographer who had written his doctoral thesis on the British automotive industry, he found a great deal of research interest in New Zealand and the Pacific Islands. He also found Elizabeth.

Elizabeth and Gerry were married on 3 February 1967 in Suva, Fiji, where Elizabeth's parents were still working. For the next two years Auckland was the place of residence and work for the young couple. 1968 brought two momentous events to their lives. One was the birth of the twins in May. Coinciding with that wonderful milestone was an invitation to an appointment to the new University of Guelph, which had been formed in 1964 from the Ontario Agricultural College.

The story of the arrival of Andrew and Victoria must first be told. Elizabeth's pregnancy had been normal; she had continued to work as a university lecturer. In her fifth month her doctor encouraged her to make a research visit to the Pacific Islands. A move to a larger apartment took place in her seventh month. Elizabeth was active and in excellent health. Then came the early "baby alert" and Elizabeth entered the National Women's Hospital. The babies were considerate; they allowed Elizabeth 12 days of rest before making their formal entrance. Labour lasted 14 hours, without complications. Medical care was state-of-the-art.

Andrew John weighed 4 lbs 10 oz, 6 ounces more than his sister; they remained for 5-6 weeks in the hospital's premature unit. Andrew again led the way by coming home first. For their first six months, the babies were closely attended by experienced people. Once home, they were visited weekly for some months by a senior nurse of the New Zealand Plunket Society. The Bloomfields also employed an experienced Karitane nurse, for three days a week.

Current hospital policies did not allow Elizabeth to breastfeed the premature babies, so they were nourished on cow's milk formula, with solids introduced at 3.5 months when Andrew weighed 11.5 lbs. First solids at this time were: vegetable puree; sieved cooked liver, beef, egg yolk; seameal custard; mashed banana; cooked fruit pulp; baby rice and barley cereal. At 4.3 months, Andrew weighed 13 lbs 4 oz and the nurse noted in her record book: "Big gain, well and happy, vocal, more active." He was rolling over at 20 weeks and at 25 weeks (the last checkup date in his New Zealand baby record book) he weighed 19 lbs 3 oz. During his first six months, Andrew sometimes had acute problems of constipation, but also

occasional diarrhoea--in spite of the approved and varied diet. (This dietary history may be significant in relation to the hypothesis that autism may be induced or at least complicated by intolerance of some foods and/or chemicals, including wheat, cow's milk and sugar. The body may appear to accept these substances, but they cannot be properly digested; toxins escape through a so-called "leaky gut" and act like opiates sending faulty messages to the brain, causing perceptual problems and chronic anxiety).

Andrew was always different from his sister but, as new parents, Elizabeth and Gerry did not see great significance in this. They were glad that each twin had his/her own personality. Perhaps, if they had been experienced with young children or if they had more family around them to advise, they might have taken the differences more seriously. They recall that the staff in the hospital's premature unit were full of enthusiasm for Anne Victoria who fought for her life and was able to charm the people around her, as she did throughout her life. The senior Plunket nurse who made those first visits offered to take Andrew to her home and care for him one weekend. Was she specially concerned about Andrew, and wanted to observe him more closely? She had tested him for PKU on her first visit and may have wondered then if the results were not satisfactory. Elizabeth recalls that the Karitane nurse found it much easier to relate to Victoria than to Andrew. Neither nurse ever expressed their thoughts about either baby. Yet differences in the children were there.

What were these differences? Most obviously Andrew was not cuddly. When people started to pick him up, his body would be awkward and stiff. While he made good progress with weight gain and other baby milestones, he was two weeks later than his sister in rolling over; he did not smile early as did his twin. Andrew followed a different timetable, too. He did not want to settle to sleep in the evening. It was during these wakeful evenings that Gerry and Elizabeth noticed that he liked classical music. Schubert's "Trout" in particular had power to soothe him, as it still does. Andrew always showed extreme sensitivity to sounds. He was neither aloof nor remote; that developed later. There was plenty of eye contact with his parents. In early photographs, he smiles into the camera.

The Bloomfields left New Zealand when the twins were six months old, eventually arriving in Guelph after two months en route via Australia, India and Russia (for conferences and fieldwork) and England to visit Gerry's parents whom he had not seen for close to five years. Before the Bloomfields left New Zealand, Elizabeth's parents came to Auckland in September to meet their first grandchildren who were then four months old. In preparation for the marathon trip across the world, the twins were immunized against diphtheria, pertussis, tetanus, polio, smallpox and cholera in several shots between early August and late October 1968. They had no adverse reactions to these immunizations. During the time of

travel the twins were given VIP treatment, but along with Dad picked up the "Delhi belly" bug. It was difficult to get thoroughly boiled water in India and Russia. The bug kept company through their stay in England; they were all well by the time they arrived in Canada.

Travelling across the world with twin infants was an adventure on which the Bloomfields embarked with confidence. At the time, they assumed they would travel often in their future family life, probably revisiting New Zealand and England and travelling elsewhere on sabbatical leaves as university families did. As things turned out, they have been tied to Guelph, a place they never imagined would be home for 30 years. Gerry and Elizabeth have made separate journeys, mainly to visit their parents and other family members in England and New Zealand; Vickie accompanied her father on two trips to England in 1979 and 1990. Since Gerry and Elizabeth have never flown anywhere together since arriving in Canada and have had very few holidays, it is good they took their 1968 trip.

The Bloomfields began their lengthy journey in Australia, where they looked up relations of Gerry's father and visited his grandfather's grave at Auburn in the Greater Sydney area. (Gerry's father has published an account of how the Bloomfields went to Australia in the 1920s in his family history, *A Story to Tell*). They spent a few days in each of Melbourne and Perth, with ex-Auckland friends the Conachers in the latter city. From Perth they flew by Air India via Singapore and Madras to Bombay where they stopped for several days. Then it was on to New Delhi, where Gerry was on the program for the congress of the International Geographical Union. Air travel and hotel accommodation were excellent. In the New Delhi hotel, the twins were cared for during the day by an Anglo-Indian ayah for a few days, allowing their parents to explore the city and area, also travelling by train to visit famous monuments, such as the Taj Mahal in Agra.

When the Bloomfields had booked their journey five months before, it had seemed good to plan a flight from New Delhi to London, England by way of Moscow. The Russian invasion of Czechoslovakia shortly afterwards stirred uncertainty. They were practically the only passengers to get off the Air India plane in Moscow in early December. They immediately noticed the large numbers of troops being organized into outgoing planes, presumably bound for Prague. Elizabeth says, "I remember how they noticed us too, especially the twins who were warmly and attractively bundled up, and also the softened expressions on the fresh faces of what seemed to be young country lads... Driving in from the airport, we were struck by the complete lack of billboards and the regimented rows of apartment buildings."

The family was booked at the Metropole, a hotel built in the Tsarist times on Red Square. Arrival with the children prompted the sudden flocking of about 30 female employees to the hotel lobby. While Gerry was busy checking in, Elizabeth

was bombarded with questions about the twins and their travels, through an interpreter. "My clearest memory of Moscow is of the many older middle-aged women overcome with sentiment by the sight of the twins," Elizabeth recalls. "We also observed people we assumed were party functionaries living it up in the hotel dining rooms." Gerry's strongest feeling about their time in Moscow was profound unease as he walked alone around Red Square while Elizabeth stayed with the children in their hotel room. For several reasons--Gerry's unease, the quality of service being at a standard far below what they had booked and prepaid, and the "Delhi belly" bug continuing to stir up trouble--they decided to cut short their time in Moscow. There was no problem getting seats on the British Airways plane; it was nearly empty. This was also the last Comet flight between Moscow and London. And for Gerry there was profound relief. His family was OUT!

Shortening their stay in Moscow meant more time with Gerry's parents at Arnside in the lovely English Lake District. For three weeks, Grandmother and Grandfather could enjoy Andrew and Vickie and share in their first Christmas. During this visit, also, the children received baptism by the local Methodist minister.

It was very cold midnight in early January when the plane landed at Toronto International Airport. Dressed in a Russian fur hat and an Australian sheepskin coat, Gerry descended from the plane, a snowsuit-clad twin under each arm. Elizabeth followed, also clad in fur hat and sheepskin coat. They had no overshoes. The stormy sweeps of snow and intense cold brought memories of Moscow and its gloom of cold, poor food and accommodations. However, they were warmly greeted by Fred Dahms, chairman of the Department of Geography at the University of Guelph, and his wife Ruth whom they had known when Fred was doing his doctorate at the University of Auckland in the mid-1960s. Arrangements had been made for the Bloomfields to occupy the house next door to the Dahms while the neighbours were away on a Florida vacation. Physical affirmations lend comfort to any new beginning.

Gerry and Elizabeth later rented an older house near the Public Library in downtown Guelph for three months before buying their first house which is still their home. The children were approaching their first birthday when they moved into their split-level home. Both were mobile, Andrew having reached the milestone of walking ahead of his sister. He was agile, less prone to the falls and collisions of that stage of baby life than was his sister.

Soon after their arrival, the Bloomfields tried to find the kind of health care for children that they had experienced in New Zealand. Their new doctor's attitude was: "Call me if anything goes wrong." Friends told them that was typical of the medical system. Elizabeth says, "We now wonder if the New Zealand system might have detected signs of Andrew's problems earlier. We noticed the first major

signs that all might not be right with Andrew during the summer of 1969, within three months of moving into our new house."

Traumatic nights began during the very hot month of July 1969. Andrew screamed and tantrumed at night; he could not be comforted. The doctor came and diagnosed "Constipation!" However, Andrew did not then have the usual symptoms, and the obvious remedies did not ease the distressed times of tantrums and screaming. From this time he was often hyperactive and in perpetual motion. In bad times and in better times as well, he found it hard to go to sleep. He would rock himself against the headboard of his crib with great force. Soon the crib would be sailing around the room, which then had a hardwood floor. At times he would crouch on all fours and use his forehead like a battering ram on the headboard. He was apparently oblivious to any pain. Sometimes Andrew sat up with his back against the headboard, rocking against it with his shoulders and the back of his head. He also rocked when sitting on the floor and leaning against the wall. Dented and broken plaster or drywall marked the force that the child could engineer.

What could have initiated this behaviour in Andrew? It was summer and with the season came high temperatures to which Andrew responded with great sensitivity, demonstrated in hyperactive behaviour. Changing his room to the lower level of the house brought some comfort. Air conditioning was later installed in 1977.

Looking back on that summer of distressing behaviour, several thoughts come to mind. First, the doctor in July 1969 perhaps was more right than he knew. Were Andrew's actions consistent with some symptoms of allergy-induced autism including sensitivity to such foods as wheat, dairy and sugar? It would take many years before these food intolerances finally were defined in Andrew.

A question that comes to all our minds is how to explain the terrible "self abuse"? When Andrew was young, such behaviour was called "self-stimming", a term to explain that he was trying to get sensations he otherwise lacked. His threshold of pain was definitely high, so that he was able to tolerate the dreadful head banging. The rocking may have helped him get to sleep. If Andrew was sensitive to foods, it is possible that the head ramming was a response to the mangled messages his nervous system was sending to his brain because of the food toxins in his bloodstream.

Further problem signs developed in Andrew at the time that children usually begin to utter speech sounds. These became obvious in the differences between Andrew and his sister. Andrew started with perfect enunciation of a few words and phrases. He stopped there while Vickie developed in the expected manner: babbling words, then phrases and sentences. Andrew would utter more whenever he was distressed. Some common words would be used as symbols for larger ideas

or signals. For example, when he felt crowded or hemmed in by noisy people or situations, he would cry "Window, window!"

Both children liked books and being read to by Mummy or Daddy. Vickie quickly became a keen reader. Andrew liked to handle books and turn their pages. He had a passion for re-arranging books on the bookshelves by publisher, using the books by the logos or emblems on their spines. Andrew also loved large dictionaries that used line drawings as part of the definitions. Elizabeth and Gerry did not realize how important those early reading sessions were to Andrew. It was not until 1993, using facilitated communication, that Andrew was able to say that he had taught himself to read when Mummy read him stories.

Andrew related differently to objects. Sometimes he liked the boxes that toys came in better than the toys themselves. He did not twirl objects, but he spun his body. As far back as his parents can remember, he was always a whiz at puzzles. He had remarkable abilities with spatial relationships and good memory skills.

Andrew related to objects better than to other children. The Bloomfield sandbox was the gathering place for the neighbourhood children. Andrew loved to play in the sandbox, but it was his sister who related to the other children. If a child took his special toy or object, he did not protest. He simply got up and walked away. The child could have his toy. Whenever the children teased Andrew, it was Vickie who came to his defence and set the youngsters straight. After Andrew was diagnosed with autism, Vickie would state firmly: "He's NOT retarded; he's autistic."

Andrew insisted that routines be kept and that they were always kept unchanged. Mummy or Daddy must take the same route when driving to the university--at ALL times! In the supermarket, the buggy must be pushed down EVERY aisle even when only one quart of milk or a single loaf of bread was needed. Deviating from what he knew to be the regular route or pattern resulted in a catastrophic temper tantrum. On the road the car would rock dangerously. In the supermarket Andrew would throw himself on the floor--and there would be startled looks and disapproving stares. Later it was perceived that Andrew's need for routine was his way of achieving some familiar order in a situation or circumstance which to him was confusing or chaotic.

Vickie's loyalty and mature understanding of her brother displayed itself not only in the sandbox but also in the community. When the twins were just three, Elizabeth took the children with her to the Dominion supermarket. While she was collecting things from the shelves to place in their cart, Andrew suddenly was gone. "Stay with the cart," Elizabeth told her small daughter, "I must find him." Elizabeth disappeared out of the store and into the parking lot. The few minutes seemed like an eternity and Vickie began to cry. Some kind people noticing her,

asked, "What is the matter, dear?" Vickie, continuing to cling to her cart, told them. They would go with her to find Mummy and Andrew, the people told Vickie. However, Mummy had told her to stay put - and NEVER, NEVER to go with strangers. . . . The people stayed with Vickie until Elizabeth, with Andrew in hand, returned. The nice people then told the story, being full of praise for the little girl's determination to do the right thing.

On his own, Andrew frequently took off from home to explore the neighbourhood. Though the Bloomfields had fenced their lot as one of the first tasks, most lots in the new subdivision were still unfenced and it was easy to slip between the houses on his adventures. It was also hard to find him. However, the small boy had an excellent sense of direction; he had no trouble finding his way home from parks in a one-mile radius.

Andrew often seemed oblivious to other people. He might not respond to them, even though he might react to some distant sound. Early photos, in which he is seen smiling, show that he did relate to his family at times. Then there were those rare occasions when he showed a special empathy and affection for his twin sister in his preschool years. One was at Guelph's Riverside Park East where Elizabeth often took the children to play on the swings and roundabouts. It was nearly 3 kilometres from home. Sometimes Elizabeth pulled a wagon or sled in which the twins could take turns to ride for part of the way. Sometimes Andrew pedalled his red fire engine while Vickie rode her tricycle. This time their grandfather from Fiji was with them, and they went by car to the park with its swings. When it was time to leave Vickie decided to swing on. The rest walked towards where the car was parked expecting that Vickie would follow. She did not. They started to get into the car thinking surely Vickie would now come. She continued to swing back and forth. Suddenly in distress Andrew broke away and dashed back to his sister. The swing had stopped and now Andrew took her hand, calling "Toria come."

While the days were filled with exhausting and anxious activity, the nights offered the family little respite. For Andrew had sleeping problems in which he was wakeful and hyperactive until 1 or 2 a.m. Once finally asleep, he would not awake until 11 a.m. If he were put to bed too early, before he was ready to sleep, he tried to rock himself to sleep. Too often the rocking was so energetic that his bed would fall apart. He then was more wide awake than ever.

Andrew's perpetual motion, day and night, was not only in his physical motor behaviour. He became hypersensitive to tiny specks of dust or lint on his clothing. These specks, usually invisible to others, he picked off, one by one by one.

As the signs of Andrew's problems mounted, as did his parents' weariness. Elizabeth and Gerry looked for solutions, increasingly worried about their son. The

doctor had said: "Wait and see until he is three." The neighbours and friends said: "There can't be anything wrong with him, he looks so bright." Another comment was "Einstein didn't speak until he was three." And so their fears would be allayed--for a time.

2 *LEARNING ABOUT AUTISM*

Andrew was nearly three when Elizabeth and Gerry read reviews in English newspapers of a new book about autistic children. The author Lorna Wing and her husband were psychiatrists, and thus had both professional and personal experience of the subject as their daughter and only child had autism. The Bloomfields noted that the diagnostic elements of autism, described in the book, matched their own experience with Andrew. First, there were his difficulties with communication and social relationships and in his development of play and imagination. Secondly, there was Andrew's roaring resistance to any change in routines. Pictured on the jacket of Wing's book was a young boy beating a drum. The child's faraway expression looked like Andrew's! Now Gerry and Elizabeth got a referral to a local paediatrician and suggested the possibility of autism to him. He prescribed the drugs Ritalin and Mellaril. Andrew's hyperactivity increased; his lack of eye contact was aggravated. So the drugs were discontinued. Finally, there was a referral to the Hospital for Sick Children in Toronto and eventually Andrew was diagnosed with classic autism. It was July 1972; Andrew was now four.

Andrew's diagnosis was at last made, but now came the search for a support service. Locally and in the region there were none. They heard of the new Autistic Unit ("House 17") at Thistletown Regional Centre in Rexdale at the western edge of what was then called Metro Toronto, and an hour's drive from Guelph. Elizabeth and Gerry could only make application--and wait. Finally, nine months later in April 1973, Andrew was admitted when almost 5, and he remained until early January 1975.

Gerry and Elizabeth drove Andrew back and forth to Toronto, so he was home each weekend from mid-Friday afternoon until late Sunday afternoon. Thus began the family's burden of long-distance driving to autism services that was to last until early 1997--and that took Vickie's life on an icy winter evening a year earlier. The Bloomfields also began to know the "medical model" of service, in which parents are patronized or disregarded and left to feel responsible for all of their child's problems. Sending Andrew so far away was not an easy decision; it was the only choice that could be made.

By April 1973 Gerry and Elizabeth were extremely weary. Daycare or nursery school had been out of the question because Andrew's behaviour would not

make him acceptable. There were no holidays and they had to take turns going out. Elizabeth taught university courses for six years at Guelph in the fall and winter terms from 1969 to 1975--her classes scheduled in the evenings, when Gerry cared for the twins. Elizabeth's earnings helped pay off loans and second mortgages on the house; it also allowed her to get away from the house for a few hours. At home they developed the basement and in the garden erected fences, vital to keep Andrew safe while also giving him fairly free range for his perpetual motion. With Andrew at Thistletown, there was reprieve for the family. The weekdays gave Vickie uninterrupted time with her parents and scope to develop her unique personality. She became a member of the first class of French Immersion students in Guelph.

Thistletown Regional Centre is an institution that began in the 1920s as a place where children with TB and related illnesses could benefit by country air and fresh food such as milk and vegetables. In those years Rexdale was a rural place. Through the years the institution changed its focus as the needs of children also changed. It was a treatment facility for disturbed children, when the new unit for children with autism was built on in the early 1970s. Andrew was one of 12 children between the ages of four and six who lived in the attractive, well-equipped house which combined double bedrooms on the main floor with classrooms and other activity spaces on the lower level.

Staff at House 17 included specialists in speech, social work, education, psychiatry, child care and psychology. These were the days of classic behaviour modification, with some hangover traces of the "refrigerator parent syndrome" as a residual explanation of autism. In behaviour modification, the strategy was to train the child through repetitive trials with positive reinforcers. Up to 8,000 trials would be made to get the child to say a sound like "Ba," with tiny cut-up portions of chocolate candy Smarties as rewards. Task analysis was used to identify all the steps involved in self-care tasks which people in general learn and practice automatically. Andrew had to learn to brush his teeth in 17 conscious steps, which he accomplished.

At Thistletown Andrew had two 45-minute sessions of school each weekday. The first session stressed group and peer interaction and gross motor activities. The children also had singsongs. The second session, in a smaller group, focused on academic skills. It was obvious to his parents that the caregivers and teachers cared very much for Andrew.

The month following his arrival at Thistletown, in May 1973, the House 17 staff had urged Andrew's parents to take part in the research-and-diagnosis exercises organized by Dr Bernard Rimland at the Institute of Child Behaviour Research in San Diego, California. Rimland has an autistic son, a unique qualification for the research as people without personal experience can never

understand quite what it is like to live with autism and how it removes the family from the mainstream of society. Responses to Rimland's questionnaires were analyzed in San Diego and the results confirmed Andrew to have "classic autism". At that time Gerry and Elizabeth were aware of Rimland's research into megavitamins and diet, and of the idea of a link between allergies and autism. Diet was a factor they would investigate many years later, but at the time the professionals around Andrew discouraged them from pursuing any of these lines.

During his 20 months at Thistletown, Andrew lost virtually all his speech--a development noted with regret by his caregivers and teachers. They were concerned also that he was so profoundly sad while he was away from home. He lost his appetite--for the only time in his life! Photographs at this time show a thin, pale, strained little boy compared with the robust and rosy photos when he was younger. Through Facilitated Communication in the 1990s, Elizabeth and Gerry came to know that Andrew hates living away from home, and that he can be distressed by the noisy behaviour of others with special needs.

Another pattern that showed his homesickness was withholding bowel movements while away from home and saving them for the weekends when he was in familiar and quieter surroundings. This became a longterm characteristic and a serious problem, at times. In October 1973, while at home for the weekend, Andrew had a serious attack of gastritis and had to be hospitalized in Guelph. This was a traumatic experience for everyone, including Elizabeth's parents who were visiting from Fiji. This was first visit together of Marama and Turaga (their Fijian titles); they had made separate visits in spring 1970 and autumn 1971.

Elizabeth's parents had offered to stay with Vickie who would be at home (and at school by day) during the week when Andrew was in Thistletown. A few days in Ottawa would have given Gerry and Elizabeth their first holiday. Andrew's illness made the trip impossible--much to Vickie's relief, as she confided afterwards. She did not know her grandparents very well and had prayed to God that the trip would not take place. She added that she did not mean that Andrew would be so ill. As for the gastritis, the cause was never determined, but now might be understood as a manifestation of Andrew's hidden food sensitivities. Another terrifying experience in that period, for Andrew and for the nursing staff who cared for him, was his hospitalization at Toronto's Western Hospital to have his tonsils out. It was an experience no one could forget, and Andrew continues to be wary of hospitals and health care professionals.

Observations of Andrew in his pre-school years, reported by Elizabeth and Gerry in filling in Form E-2:a for the Institute of Child Behavior Research in San Diego

** Andrew had abnormally strong reactions to bright lights, bright colours and unusual sounds which upset and distressed him, though at times he could appear to be oblivious to some sounds (making us wonder if he was nearly deaf) but also to sensory stimuli.*

** He would rock rhythmically for hours in his bed.*

** He would "look through" or "walk through" people as if they were not there.*

** At age 3 or 4 he could be described as "lost in thought", "in a shell" or "unreachable".*

** In his first two years, he had been stiff and awkward to hold, tending to resist by arching his back and holding his head back. We added that, at 4 1/2 years, he could respond a bit to tickling and, during bedtime stories when he was weary and relaxed, could become relaxed and almost "cuddly". At this time, we also sensed that he was becoming a little more sensitive to affection or criticism.*

** He showed a remarkable memory for names, places and routes.*

** He had exceptionally good fine motor skills, and would line things up in precise rows and insist that they not be disturbed. He would notice imperfections and try to correct them. But he did not spin things or jump up and down gleefully (as some autistic children were reported to do).*

** We had early introduced him to puzzles and packs of educational cards which he would stack and sort for ages patiently and precisely.*

** He showed a strong liking for listening to music and was fascinated by certain mechanical objects.*

** He would get very upset if interrupted at what he was doing and by things that were not right, just so, or in their proper places. He demanded that the same routes be followed or books be arranged in bookcases in special ways (he wanted them sorted by publisher).*

** He was definitely not physically pliable, and seemed happiest when left alone, indifferent to being liked, aloof and remote.*

** By age 5, Andrew seemed to meet people's eyes when they talked to him, after two years of being aloof and remote.*

** He was fearful of dogs or other creatures that moved suddenly or made loud noises.*

** While a very active and daring child in running and climbing, he seemed to be surprisingly safe. He never had any traffic scare in his explorations of the suburb and never got lost. He could find his way back from the neighbourhood park by age 2.*

** His frightening temper tantrums continued to age 4 and a half when, we noted six months later, they seemed to become less frequent and less violent. Sometimes the tantrums seemed to be precipitated by frustration over specific stimuli, such as*

when we had to take a different route in the car from the one he expected, or when he was asked to do or end some activity.

** He did not hit, bite, punch or otherwise injure himself or others (except that the back of his head and shoulders must have developed some callouses from rocking against headboards and walls).*

** His first six words had been CAR WINDOW NO BATH BOOK LIGHT, but he did not use the word YES. He might use a single word with a simple meaning to mean something more. For example, if he felt crowded or hemmed in and wanted space, he would say WINDOW persistently.*

** Before age 2, he seemed about to start speaking, with his early utterances being very well enunciated (with no baby talk); then he seemed to tail off in his spoken language.*

** He seemed able to understand what we said to him, judging by his actions and responses.*

** He would point accurately to most familiar objects we named.*

** He seemed to think of himself in the third person, a feature interpreted as revealing problems with self-image, and for years called himself "Andoo" or "AB" with sign and later with Facilitated Communicating.*

Those Thistletown years seemed to produce questionable results. There were repetitive trials to get Andrew to vocalize single vowels, syllables or simple words in return for the reinforcement of particles of Smarties. But these efforts seemed wasted, when in 1975 the emphasis in his communication program shifted from stimulating vocal speech to sign language. However, one lasting success of the applied behaviour modification techniques was a toilet-training program designed by Dr Jeff Sherman and implemented at home, about the time that Andrew left Thistletown to live full-time at home again. He became fully toilet-trained by day.

In these early years, special education was not mandatory and there were no services in Guelph until January 1975 when the local Board of Education established a special Autistic Class. Andrew was a charter member. For several years Gerry and Elizabeth had been advocating for such a class. From 1972, also, they were associated as founding members of the Ontario Society for Autistic Children (now Autism Society Ontario). Gerry was a charter director of OSAC and much involved as vice-president, president and past president through its period of establishment and growth until 1990. As for Elizabeth, she was active in the formation of the Waterloo-Wellington chapter of the provincial society. When OSAC decided that chapters should coincide with Board of Education areas, Elizabeth did much to organize the Wellington County chapter and remained a mainspring until 1987. Thus through the 1970s and 1980s, the Bloomfields were well informed of new developments in the field of autism (such as the origins of

both The Geneva Centre and Kerry's Place Autism Services in 1974) and well connected with experts and services.

Elizabeth and Gerry have worked steadily for their son's needs and for the needs of others with autism and their families. Their own needs have all too often been overlooked. Their efforts to join local churches were thwarted by people's perceptions of Andrew's behaviour. Elizabeth says, "If we had already been part of a congregation before the children's birth, it might have been different. But we came to Guelph complete with family and autism."

Elizabeth continues, "Conventional social activity was impossible. When we came to the college town, polite gatherings of faculty and their wives were de rigueur. One Dean's wife took it upon herself to rebuke Gerald for his wife's absence from these gatherings and to suggest that "a little black dress" would do very well. When we did contrive to get out to some social occasions, they could seem so remote from our experience and interests, especially when we returned to another sleepless night. Far from being enjoyable, social occasions only underlined our sense of isolation. With Andrew, our whole family suffered from autism. Many academics and university people who prize intellect above all else find it very hard to cope with either the idea or the reality of someone who is or seems intellectually or mentally handicapped. We understood this attitude, and would probably have shared it, if Andrew had been normal. But it was a glass wall between us and our colleagues and associates, however kind they were. We did not want to make Andrew's autism an excuse for anything, and so suppressed any impulse to share our problems. It is probably only since Vickie's death that people have come to understand a bit more how differently life must be lived by people with autism and their families."

3 *SCHOOL IN GUELPH*

Elizabeth's and Gerry's long-distance chauffeuring of Andrew to and from Thistletown--in rain, snow and summer heat--came to an end in early January 1975. Andrew was now home to stay. He was six years and eight months old, at an age for school. Gerry's efforts in the previous year or two to advocate with the local Board of Education for a school place had produced results. Andrew became a charter member of a special Autistic Class, which was first located at Edward Johnson Public School, then moved three years later to John McCrae Public School. Its teacher, who was from Brisbane in Australia and became a good family friend, continued to teach the class for more than ten years. She was assisted by a succession of teacher aides, usually two at a time. Andrew still remembers their names.

The first of these schools was an excellent experience, for the principal and staff appealed to their pupils' co-operation with the idea that their school was specially privileged to have the Autistic Class. Andrew and his classmates were integrated with the school's other classes for some of the school's activities. Also, each autistic child was teamed with individual Grade 6 students who acted as companions in recess times. The Grade 6 students competed fiercely for the privilege of being responsible for an autistic child. Andrew's first Grade 6 friend went on to qualify in speech pathology and earn a PhD degree in psychology, and credits her experience with Andrew as a key factor.

In the summers of 1975 and 1976 special programs were sponsored by the Integra Foundation for young autistic children. This service formed the nucleus of the agency which would become known as The Geneva Centre. Andrew was selected as part of the small group of young campers in the lake country north of Haliburton, Ontario. These were times when he received intensive attention from people practising then state-of-the-art techniques. The most enduring effect of these camps was the decision to focus on developing sign language (Signed English) rather than trying to stimulate vocal speech. Another lasting result was the reinforcing of his dislike for certain foods which are of similar shape: peas, round or kidney-shaped beans, and most forms of cooked egg. These food items were used in the summer programs to teach Andrew consistent use of the signs for "Yes" and "No".

Andrew's time at each summer camps gave his family a much appreciated break and opportunities for a few days' holiday travel in the region around the location of the camp. They went to Kingston, Ottawa and Montreal, cities Elizabeth and Vickie had not previously visited.

After each three-week summer camp, The Geneva Centre's staff continued periods of follow-up, which were most helpful to the classroom teachers. In the Autistic Class, Signed English continued to be the basic means for communication and for learning. Andrew quickly learned perhaps as many as two thousand signs, and has been hailed by staff in his various programs their walking Sign Dictionary. While he was adept at imitating and remembering the signs, he would not often initiate them to communicate. His family recalls everyone's joy when he used his first spontaneous sign—for toilet or washroom. He still likes to signal his intentions with this sign!

The school years in Guelph were generally happy years for Andrew. As part of the school activities, he enjoyed swimming and skating, cooking and music. These, with arts and crafts, were continued in the summer day camps organized by Elizabeth for the Wellington Chapter of the Ontario Society for Autistic Children each year from 1977. The first summer program served seven children with

learning disabilities as well as for the five with autism—making a more viable number for transportation and other logistics.

Elizabeth was involved in organizing Guelph's first integrated summer day camp in 1978, as treasurer and a director of the responsible charitable corporation, Rainbow Programmes for Children. Originally the brainchild of Paul and Wendy Young, Rainbow has continued to offer summer day camps for children up to age 12, a proportion of them having special needs. From the beginning, however, it was necessary to negotiate special funding so each child with autism could have his/her own counsellor. As in many other group settings, it was often hard for counsellors and other children to understand the particular needs of autistic youngsters who could be frustrated by the pressures to conform to group activities they did not understand.

At home there was always music to enjoy, puzzles, books and family table games. Interestingly, Andrew had no desire to watch TV! He continues, as an adult, to relax with books, music and games. He does not choose to watch TV, but will join his family occasionally to watch the news and a few other programs, for mainly social reasons. He is certainly interested in current events and general knowledge.

Andrew turned 12 in 1980. At this time, the Autistic Class had 8 children, ranging in age from 4 to 15. For the older ones in or entering puberty, individual attention was hardly possible. The Bloomfields and other parents tried to persuade the Board of Education to start a program appropriate for autistic teenagers in a High School setting. The Board was not prepared to set up such a program then, but did so in 1984, too late for Andrew and his peers.

Outside school hours, there was no help or occasional relief. Babysitters had to be extraordinary to cope with little children with autism. We lack a word for the equivalent service for teenagers who need special care and companionship. Special-Services-at-Home funding, which later made it possible for families to hire students or others as tutors for some supplementary hours, was not yet widely available, though Elizabeth administered some funds and staff for other Guelph children from the mid-1970s.

The Bloomfields had tried to find some respite service for Andrew, so the rest of the family might have small breaks of a few hours to a few days. There was even a plan to revisit New Zealand in 1978, ten years after coming to Canada, to share in celebration of Elizabeth's parents' 40th anniversary. But no agency would accept Andrew for residential relief. (Instead of travelling to New Zealand, the Bloomfields had themselves photographed in a studio, the second of only two photographs ever taken of all four of them. One Bloomfield always had to be the photographer).

Only the new organization of Extend-A-Family, led by Phyllis Sharratt, took an interest. The Bloomfields were teamed with a host family who lived in the country on the other side of Erin, and were very interested in learning about autism. Andrew and Vickie made a few visits there in early 1980 to familiarize everyone with the idea of an overnight stay sometime. Andrew's fear of dogs made these somewhat anxious times. The host family was very kind, but moved away from the region soon afterwards.

Without appropriate services locally, parents had to look outside their community for help for their autistic teenagers' special needs. One boy of Andrew's age was sent away to a small care facility run by his family's church in the Chicago area; he became ill and died there within a few months. After nearly six years of living full-time at home with his family, Andrew also left home, and once more began the weekly long-distance drives--in all weathers.

4 *KERRY'S PLACE AND ST FRANCIS HOUSE*

The Bloomfields applied to Kerry's Place, then a residential school for about a dozen adolescents, which had been founded by a group of parents and was funded as a Children's Mental Health Centre. Named after the daughter of the family on whose farm the school was established, Kerry's Place was located in Clarksburg in the Beaver Valley of Grey County. Gerry and Elizabeth did not hold much hope that there would be a place for Andrew there. However, in late 1980 a vacancy arose when some Kerry Place graduates moved on to a new adult centre. This was Adam's Place near Orangeville, opened by the Kerry's Place non-profit organization that took its corporate name from its first residential centre and expanded it to Kerry's Place Autism Services in the mid-1990s. Andrew was chosen to fill that vacancy, and so for the next four years his life was divided between the residential school program in Clarksburg and weekends and holidays at home. In September 1984, Andrew's school was relocated to Maple in York Region. This meant a longer distance for travel, and over busier highways.

When trips could be fitted with trips made from Wellington County to the E.C. Drury School at Milton, Andrew was transported by drivers of Cook's bus and taxi service in Mount Forest. However, for at least half the trips, Gerry or Elizabeth drove him back and forth, Elizabeth driving directly to Kerry's Place or Gerry meeting the Kerry's Place van in Toronto on Friday afternoons. It was a great deal of driving over many years, but the Bloomfields were thankful that Andrew had a school program designed to meet the distinctive communication and behaviour challenges of autism. The weekly rhythm was fairly predictable, a plus for Andrew who did not like changes in his pattern of life. It was not until Andrew began to

communicate through FC, that his family came to know how much he disliked living away from home. They feel regret about this, though they had done what was right for their son at that period in his life and with the services available to him. Another reason for accepting the Kerry's Place vacancy was to give Vickie scope to develop her abilities and some time with her parents when Andrew's needs did not always have to come first.

We might ask why did Andrew not return to Guelph for his schooling when a class was established for teenagers in 1984? Two teens with autism in the 1984 class did not settle well into the Guelph program and transferred to Kerry's Place in Maple. So Kerry's Place seemed the right place for that time for Andrew.

During those teen years Andrew was fortunate not to have behaviour changes or seizures, symptomatic of traumatic adjustments at puberty. He grew tall in those years. From 4'10" in August 1979 he went to 5'3½" in August 1981. The following May, in 1982, he was 5'8", 1½" more two years later. In February 1985, when he was 16 and a half, he was 5'9 ½" and continued to grow during the second half of the 1980s until he reached his present height of 5'11".

Physical measurements are easy to ascertain; it was good to see that Andrew developed normally. Judging by his behaviour he made positive adjustments to the changes in his teen years; he appeared happier at Clarksburg than he was at Maple, yet the latter had the advantages for staff of being closer to Toronto-centred expertise. During the Maple years, Andrew had interesting vocational experiences, including helping in the Maple library and the local high school library. These reinforced his longstanding and continuing love of libraries. Books, of course, had always been a part of Andrew's life, as shelves of books lined the Bloomfield home.

Allergies became a problem for Andrew during his time at Maple. Was there an environmental cause, from the experimental feed grain farms next door? Food allergies were never suggested. It is interesting that whenever Andrew was home he did not show signs of allergies! The Maple staff devoted a lot of time to graphing behaviour, and trying to relate specific behaviours to specific causes. Problems around food and mealtimes might reflect Andrew's irritation by the noise and dysfunctional behaviour of others. Out in the community, when he encountered or even suspected the presence of dogs, of which he was terrified, he might run away very fast without watching out for traffic.

Vickie grew much closer to her twin in their later teen years. From the mid-1980s she gave Andrew a good deal of very helpful attention and companionship at home. She developed with him a course of pet therapy with the help of their neighbour's dog. She did this to help him overcome his terror of dogs; this was to enable him to go out happily into the community where he could be involved in activities that would add structure to his days. Andrew's ability to move around the

community was the best achievement and most helpful development of the decade of the eighties. The story of Vickie's first great achievement for her brother merits its own chapter to come.

The purpose of Kerry's Place was to serve adolescents. So from about 1986, when Andrew was 18, the Bloomfields were under pressure to find some adult placement or program for their son. In 1980 they had been instrumental in setting up a not-for-profit corporation with a focus on adolescent and adult needs. They kept in continuous touch with any and all existing services. Many Kerry's Place graduates went on to the organization's adult centres. For Andrew there were no vacancies. In any case, Guelph was in the Waterloo Area and Southwestern Ontario, outside the catchment areas of any Kerry's Place adult centres, and without any services designed for adults with autism.

Then in the fall of 1989 Andrew was offered a place in a new group home being organized and built by the St Francis Advocates, 3 km east of Petrolia in Lambton County. Gerry and Elizabeth counted themselves lucky with this good news for Andrew. With the hindsight of FC they came to realize some negative aspects of this new move. First, Andrew moved from Kerry's Place directly to St Francis House in late October without a transition period, difficult for one who found change a high hurdle. Also, the group home was far from his home, and the distance between St Francis and Guelph was too great for Andrew to come home every weekend. Instead he came home every two weeks for a four-day visit, and sometimes winter weather conditions might reduce the visits to only once every three weeks.

Andrew settled well in a kind of honeymoon period, but then there were the exceptions. It was decided by both Kerry's Place and St Francis representatives that a continued liaison was no longer needed with Kerry's Place. Staff who had known Andrew well were no longer available for their expertise.

Group home living gave Andrew the guidance of staff who had some experience with autism. It was also planned that he would have supervised work opportunities in the community. However, there are few choices that clients can make in such a group arrangement. Timetables are set up without consultation. One must fit into arranged and assigned schedules for work, recreation, meals etc. As for all people, it is always nice to have the freedom to decide on an activity or to choose what you want for lunch or dinner. This kind of freedom could not be had.

While at St Francis House, Andrew sampled new types of work experiences such as recycling in Sarnia and stocking and tidying shelves in an independent grocery. He no longer had regular exercise, which he must have missed. With thought of Andrew, a young puppy was acquired for the group home. Puppies leave their wet trails; they are not particular where and when they produce their

puddles. In other words, the pet caused problems for the entire house and so was adopted by one of the staff. Andrew was upset by the removal of the puppy and, coinciding with this, by the terminal illness and death of his dog Angus at home. He was further distressed by the crying of a new female resident who came to the group home in late winter. Andrew's honeymoon period was quickly over. But finally summer arrived and with it three wonderful weeks at home in August with Vickie.

September 1990 rolled around and Andrew returned to St Francis. He now became moody and depressed. There were flash outbursts and aggression; perhaps he was trying to express his unhappiness to his family and staff. At this time, Temple Grandin, the autistic savant, was speaking and writing about her success with the antidepressant drug, Imipramine. Supported by Kerry's Place and other professionals, the St Francis staff began Andrew on a course of this drug. He reacted adversely and with extreme side effects: high temperatures, profuse sweating, sleeplessness, self-abuse, aggression and food raiding. To counter these negative conditions, he was given anti-psychotic drugs prn (when necessary). Andrew's distress and aggressive behaviour only increased. The winter had been a traumatic time; the staff obviously could not cope. The long-distance travel was also impossibly unsafe for Andrew and his drivers. The Bloomfields withdrew Andrew from St Francis House at the beginning of May 1991, and brought him home.

5 *HOME-BASED INITIATIVES IN THE 1990s*

Andrew was home this time for nine months at a stretch, until early February 1992. It was a challenging time for the entire family in which Andrew's parents and Vickie were his devoted and effective support team. The house in Guelph became his program base and that year some remarkable things happened which Andrew says "changed my life for the better".

Four things come to mind when we consider how Andrew's life changed. First, a tutor and companion was employed for an average 25 hours a week. A recent University of Guelph graduate from the Family Studies program, she has remained a good friend and effective facilitator. Second, the family adopted a new dog, Zachary, who continues to be a vital part of Andrew's life.

Third, in June 1991 Andrew was introduced to facilitated communication (FC) by a noted communication specialist. Another expert in speech pathology undertook to monitor and support Andrew's use of this modality. It was through these contacts that in late 1992 Andrew obtained a subsidy to lease an Epson communication device with male voice output and access to some resources at the Chedoke Technology Access Clinic (TAC) in Hamilton, Ontario.

Lastly, Andrew learned to ride and care for the horses at the Sunrise Equestrian centre. This helped him both physically and socially, and marked the beginning of various kinds of work experiences and recreational activities in the community.

During 1991, Andrew's parents tried to obtain some modest resources so that they could sustain his life at home. Their appeals, supported by various professionals who knew Andrew, failed to secure funds for more than six tutorial hours a week and at the lowest level of pay. Directors of local agencies were sympathetic but could provide no more. They recommended the only option--temporary placement at Midwestern Regional Centre, a Schedule 1 facility or institution in Palmerston. Elizabeth had a very heavy heart as she drove Andrew to MRC on her wedding anniversary in early February 1992. In his year at home, Andrew's life had been greatly enriched by his family. He was coping well with his disabilities, learning new skills and tolerances. He was happy in his stable and consistent environment, surrounded and encouraged by his own parents and sister. Now the divided life with its stop-go effects was to start once more, as well as the long-distance driving which, on a miserable winter day four years later, would lead to Vickie's death.

Institutional facilities were once admired as centres of expertise and resources for people with developmental challenges. Midwestern Regional Centre was one of the last in Ontario to be specially designed and built, in 1965, for what were then termed "retarded" children. By the early 1990s, it housed only adults--

the children of the 1960s and 1970s who had just stayed on there. The buildings and grounds were kept very tidy and clean. But MRC, like other provincial facilities for the developmentally handicapped, had been under sentence of closing for more than a decade. Residents with less challenging needs had already been transferred to other programs in the community, such as group homes and sheltered workshops. Special staff and programs had long been eliminated, leaving only basic care at MRC. There could be no therapy or development of skills.

Some MRC staff were very kind to Andrew and tried their best to help him a bit. One developed enough rapport to support him with FC, so that he could express himself there for a time. Another continued the lead set by a vocational instructor of Waterloo-Wellington Autism Services in recycling boxes at the local Co-op, and also welcomed Andrew to her house and family. But he found MRC life hard and boring. His only friends there were some staff members.

It is understandable, therefore, that weekends and holidays at home with his family were special occasions, enriched especially by Vickie who tried to balance and offset his more custodial weekdays at MRC. While pursuing her doctoral studies during the week, Vickie joyfully devoted herself to Andrew for weekends and holidays. Having her own car (the Silver Colt) from mid-1991 increased the range of possible shared activities. Some other part-time tutors and volunteers also provided Andrew with weekend experiences of skating, swimming, music, crafts and communication.

In the kind of weekend timetable illustrated here, various forms of structure gave shape and purpose to his life, reasons to get up in the morning and to pursue each activity of the day. These activities were choices he could make or agree to; they also required planning, co-ordination and confirmation by Andrew's family. A family member accompanied and transported him on every activity. For Andrew's longer periods at home, his days had a generally similar structure, thus maintaining the rhythm of life to which he could relate well.

Weekends from 1992 to early 1996 meant times for meeting with friends, for games and bike riding, outings for riding lessons, skating, trips to places outside Guelph--and "real" work, as Andrew called it. He and Vickie, for example, developed the Sears catalog routes in various Guelph neighbourhoods, a happy shared experience for Vickie's last six months (described further in the "Work" chapter").

Vickie's death in February 1996 left a terrible void in the Bloomfield family. Andrew was able to express how deeply he was hurt--even that he felt responsible for the circumstances of the accident. He showed remarkable maturity about how his twin's death would affect him. Conditions at MRC became harder, with a province-wide strike for several weeks from the end of February by OPSEU, the union of public servants to which MRC staff belonged. Andrew begged to stay

home all the time. The family was also stricken by the death of Elizabeth's father in New Zealand in mid-March, closely following several strokes suffered by Elizabeth's mother. Andrew and Gerry braced themselves to manage without Elizabeth, so that she could visit her New Zealand family in April.

Friends of the Bloomfields rallied round them in the wake of Vickie's death. They knew that the family's survival plans would have to be revised without Vickie who had expected to watch out for Andrew's best interests with and after Gerry and Elizabeth. It was also known that MRC would close soon—and this was formally announced in June 1996.

The beginnings of Andrew's support circle convened on Victoria Day in May 1996 at the farm estate of good friends near Guelph. Through several hard years from 1992, this had been one of Andrew's "most favourite" places—for hikes with Zach, swimming and boating in the pond, and visiting with friends. It still inspires his image of paradise, a haven of calm space with hues of greens and blues.

Elizabeth and Gerry asked for comments and advice on the options they could foresee in planning with Andrew for his possible future life. Friends unanimously supported a proactive approach, in contrast to just letting events unfold. They contributed ideas of approaches and contacts. Some warned against undertaking too much, on a general front as well as for Andrew's best interests. From that time, Gerry and Elizabeth have put their best energies into planning with Andrew, advocating for his plan, and supporting him to embark on his new life. The quest that starts with and always comes back to "Is it good for Andrew?" has led Elizabeth and Gerry into more than they could have expected in May 1996!

The summer of 1996 reminded Andrew and his friends of the brave adventures he had enjoyed with Vickie in previous summers. There were some day trips to favourite places such as train museums and many long hikes with Zachary. He continued to work and ride at Sunrise Equestrian. Two of his former tutors stood by him for regular meetings at weekends. He joined a new exercise program at the University of Guelph. As MRC supports were steadily diminished towards closing, Andrew spent more long weekends at home, where Elizabeth devised systematic procedures to help him learn new skills—such as making breakfast for himself and Gerry. New forms of work were developed—such as silviculture on the farm estate with Gerry and Andrew Foster who became a good friend.

Moods and behaviour were closely observed and recorded. Elizabeth and Gerry worked even harder to support Andrew with his expressive communication, in which he was doubly stricken by the loss of Vickie who had been his primary facilitator and by the controversy over FC that effectively prevented Ontario professionals from directly helping him.

During 1996-97, Elizabeth and Gerry searched for new assessments and therapies for Andrew's health, distinctive abilities and disabilities. For a long time they had been concerned about the drugs he had been given from time to time at group home and institution, and the adverse effects that they seemed produce. Andrew reacted in some distress during the high summer temperatures in early August 1996, when he must also have thought of the glorious trips with Vickie the previous summer. MRC staff administered medications over a longer period than for several years. Andrew insisted that the drugs only made him much worse; as usual, he showed signs of contrary and toxic reactions. In the fall of 1996, through a thorough assessment by Drs Huggins and Homatidis of Kerry's Place Autism Services, the Bloomfields learned that Andrew did not have a psychotic condition and thus should not be given anti-psychotic drugs.

A London allergist gave him preliminary tests, and then he was more thoroughly tested by a naturopath and practitioner of holistic medicine. The discovery that he was sensitive to wheat, sugar, dairy and potatoes (in any forms or traces) was consistent with the biochemical interpretation of autism as at least partly allergy-induced. A magnesium deficiency may be involved and an overload of toxins, caused by improper digestion, with the food substances acting like opiates in sending wrong messages to the brain. The findings may also explain Andrew's chronic problems with digestion.

In March 1997, Andrew started on a new diet, using alternatives to wheat, dairy, sugar and potatoes and adding natural substances, enzymes and hormones. The diet has succeeded, as he has generally been much more focused and more relaxed than in the past. During 1998, his sensitivities were again tested, and his need for a special diet was confirmed. He has also been helped by techniques of relaxation therapy and sensory integration. His moods are now more even and his sleeping patterns have improved. Ability to cope with anxieties and fears has increased, as has his concentration. Regular exercise, a vital part of the health structure of Andrew's life, has continued throughout.

At the end of 1996, with MRC due to close a year later, Andrew came home to stay. He had begged to leave MRC sooner than its actual closing. The drives between Guelph and Palmerston reminded him of Vickie's tragic death. As another season of winter driving began, he had nightmares and expressed fears that Elizabeth too might be hurt or killed. Elizabeth and Gerry, after some hard journeys, agreed to his entreaties. He was now entirely free of the stop-go effects of dividing his life between an institution and home. No longer did he have to cope with shifts of many staff members or with the behaviour of other residents. The small scale of a family home was easier to comprehend and experience. He has been able to share more consistently in the chores of running a home, including food preparation and cleanup, laundry and, gardening. His life now had a regular

daily structure that balances indoor and outdoor, energetic and more sedentary activities. His happiness was reflected in positive outlook, moods and behaviour.

Andrew's return home to full-time residence in Guelph coincided with publication of *Planning with Andrew*, the detailed survey of his needs and potential on which his family and friends had worked for the previous six months. Its key elements were, in Andrew's words, "a place of my own, with space and quiet," "regular structure of real work, learning and exercise", "friends who understand, believe in and help me," and ways to communicate so people "know I am smart." Monica Carsience, one of Andrew's friends and a former tutor, directed and produced the videotape, *Portrait of Andrew as a Young Man*, to illustrate his challenges and potentials.

Andrew's family and friends have felt impelled to keep up the momentum of implementing his plan for a good and fulfilling life in the community. They consider that he deserves support to make up for years of inadequate or inappropriate services. They are impressed by his understanding and participation in his plan and by his expressed wish to "try his best to be a good man." Knowing that agency and Ministry people have assured Andrew directly that his plan would make his life better, they want to keep faith with him by making these promises come true. Most of the essential features of his plan have been realized by late 1998.

Andrew has lived in his own house since the end of July 1997. Purchase, renovation and equipment of the house were financed by his parents' life savings and the house is now owned by Guelph Services for the Autistic (GSA), a charitable, non-profit corporation that is committed to supporting Andrew's lifelong occupancy. He has learned new skills in caring for himself and his house. He walks tall, expresses pride and responsibility in being a homeowner, and has taken on special roles in his neighbourhood and community.

In late 1998, Andrew is still supported in his house by his parents, with Elizabeth doing night duty and continuing with many other roles for Andrew's plan as part of her 130-hour working week. But Andrew's plan includes a household community of homesharers that has still to be realized.

Andrew has a support cluster of friends who watch out for his well-being, help him to understand and make choices, and may spend time with him on shared interests. A core group of this cluster is recognized as Andrew's House committee, a legal sub-committee of GSA.

Andrew has had his own part-time tutor from January 1997--and for up to seven hours each weekday since early November 1997. Teresa Pynenburg, who has been Andrew's tutor since August 1997, combines functions of teacher, coach, mediator, and chauffeur in a regular structure of varied work, continued learning, exercise and community experience.

Andrew and his support team have benefited from the new observations and assessments of health, nutrition and communication that became possible with his more integrated and holistic way of life. His improved health and general equilibrium on a drug-free special diet have greatly improved his outlook, moods and behaviour. His multimodal communications strategy has the goal of better all-round understanding of his abilities, challenges, options and choices.

Andrew's plan has proved to be right for him, despite very long delays in getting official recognition and adequate resources. Gerry and Elizabeth had to pay for everything during the first ten months that Andrew was at home. They even had to complete the purchase of the house that an agency had been going to buy for his occupancy, when negotiations broke down between that agency and the Ministry of Community of Social Services only a few days before the closing date. Another agency eventually took on administration of only one part of his plan; however, eight months later, its managers suddenly decided to stop supporting him at all.

Finally, 20 months after Andrew left Midwestern Regional Centre to live full-time in his home community, a mechanism to flow subsidy funds to his plan has been set up, through the kind co-operation of a distant transfer payment agency, Windsor Community Living Support Services. Andrew's plan is now not only person-centred, but also self-directed and self-administered as well. In late 1998, Andrew still needs more adequate resources so that his plan can be sustained without such overwhelming dependence on his parents.

At home in Guelph, the window to the world that was Vickie's gift to her brother has continued to widen through the loving efforts of their parents and others. Andrew continues to surprise with joy his family and friends as they discover his gifts and abilities, which once lay dormant, now changing and renewing the life of this young man.

In the remaining chapters of this book, we look at central aspects of Andrew's life plan that are also rooted in the years he shared with Vickie. Learning to care for his own dog helped him to overcome a phobia that effectively crippled his social development by preventing him from going out into the community. Two-way communication is vital for him to understand his choices and for his needs and priorities to be understood by his support team and others in the community. Andrew wants and needs real work as part of a predictable structure in his everyday life. Vickie opened windows for Andrew to enjoy his community and the larger world; he knows he needs his friends' help to continue and extend these experiences. His own house is the central focus and base of his new life.

6 *THE IMPORTANCE OF HAVING A DOG*

Two or three times a day Andrew goes on a lengthy walk in the neighbourhood or parks close by, with his dog Zachary (Zach for short). Zach runs with the happy nature and enthusiasm of his breed; he is a golden retriever and there are always many scents to explore. He lunges forward on these explorations of smells, but Andrew has him well under control. In fact, Andrew is the one in the family with whom Zach walks best. It should be added here that Zach was an obedience school "drop-out" when he joined the Bloomfield household at the age of two. However, the loving disposition of the pet makes up for such poor dog academics. Andrew enjoys walking Zach and also feeding and grooming him.

It was not always like thus, that Andrew could even tolerate a dog! In fact, since the age of three he was terrified of all dogs and would flee like the wind if he saw one or even thought a canine was in his vicinity. No one knows what happened to cause this terror of dogs. His grandmother in New Zealand has a photograph of Andrew petting a black dog, when he was two. Yet a year later the dread began. Perhaps Andrew was badly frightened by meeting a strange dog on one of his many sorties from the house to explore the neighbourhood. We may never know.

Whatever took place to cause this fear was unfortunate. For many years, Andrew became increasingly cautious about venturing out into the community. Elizabeth or Gerry might get him into the car to drive to the store or shopping mall, but if Andrew sighted a dog nearby it was useless to try to get him to leave the safety of the car. Shopping or the errand would have to be postponed.

A particularly dramatic encounter with a black dog occurred when Andrew was 16. It was March Break, always one of the most challenging times of year. Elizabeth was teaching her classes at the University of Waterloo. Andrew and Vickie had gone with Gerry to the Guelph Lake conservation area for a walk. It had been enough of a challenge to get Andrew to go at all, then to get him out of the car when they reached the conservation area, but they had succeeded. They began their walk when suddenly a wild-looking black dog came up to them and started to bark. Andrew's normal response to such a calamity was to run back to the car, but this time he ran out on the lake. It was only semi-frozen; in March it was starting to melt. Andrew ran so fast that he quickly crossed the lake, then vanished from sight. Gerry and Vickie searched for him. But Andrew was not to be found. Gerry called the police. Neighbours of the Bloomfields, Novah Flint and her son Doug, joined in the search.

As the search for Andrew continued, Vickie and Gerry saw many treacherous patches of water. It was too frightening to consider what could have happened to Andrew. Then suddenly Vickie saw him. On the ice! He was stomping

his feet on the frail support. The police were alerted and Andrew was eventually rescued.

In July of that year Vickie was bored. Summer holidays stretched before her, with nothing special to do. Elizabeth suggested that she might get together with their neighbour, Novah Flint, who had helped search for Andrew back in March. "Perhaps you could get to know her and Angus (her golden retriever); you never know, this could help Andrew".

Vickie became friends with her good neighbour and often went for two walks a day with her and 10 year old Angus. The dog was slow and very keen on scents, but he was also very lovable. Friendship grew, for Novah Flint was companionable and had a good sense of humour. She helped the Bloomfields with typing, and one day gave Andrew a special present--her late husband's bike!

The following March Vickie was getting ready to go for a walk with Novah Flint and Angus. Andrew was riding his bike, when Mrs. Flint called to Andrew, "How about coming with us for a walk?"

Andrew hesitated. There was Angus. He did not like dogs. . . Finally he got into the car - WITH the dog in it, and they drove to a nearby field. Andrew actually enjoyed walking the dog, and from that time he often went walking with Angus two or three times a day when he was at home. Angus no longer frightened him, but if Andrew suddenly met any other dog in the community he would run. Or he would refuse to get out of the car if he sensed a dog anywhere near.

Another year passed. It was March of 1987. Novah Flint had gone on a trip to Australia and New Zealand, but now returned with a strange ailment. Her leg had started to bleed in a distressing fashion. She entered the hospital for tests; it was learned that she had terminal cancer, a shock to her family and friends. Immediately they all rallied to help her. Angus remained at her side almost all the time, but Vickie and Andrew helped by taking the dog for his walks.

After their good neighbour died in mid-April, her son asked the Bloomfields to care for Angus while he went to his uncle's family in Vancouver for a time. On his return he offered Angus to the Bloomfields and the dog formally became a member of the household. Andrew adjusted well to the dog living in his home and soon co-operated in feeding and bathing him at weekends.

Andrew regained some of the confidence in moving around his neighbourhood that he had shown as a young toddler. At times when he felt hyperactive, Andrew could run fast and far. Or he would let off steam by cycling very vigorously around the crescent in front of his family home. In March 1989, he was home from Kerry's Place for the March Break--always a difficult time. On a Saturday afternoon, Andrew had returned from a long walk with Angus and Vickie when he slipped away again, and had left the home cul-de-sac for about five minutes before his absence was noticed. As his mood had been a bit volatile, the

rest of the family quickly swung into action to find him. Their search was concentrated first on the fringes of the nearby Guelph Lake conservation area where he had just walked with Vickie and Angus. They remembered the terrible adventure there four years earlier. They scoured that area, somewhat impeded by rotting ice and snowbanks, but found no traces. After 90 minutes or so, they called in the police who combed the same area. Elizabeth and Gerry took separate cars to cruise streets in the larger neighbourhood, while Vickie stood guard at the home phone.

Elizabeth tried to think herself inside Andrew's mind, to imagine where he might be bound, or what route he might take. Apart from the regular walks with Angus in the conservation area, Andrew's weekend almost always included a visit to the University with Gerry and Vickie to do some photocopying and collating. Elizabeth thought she would search in that direction. Finding no sign along the direct route for about 4 kilometres, she returned home to check that Andrew was still missing. Finally, at nearly 7 pm, she drove all the 8 kilometres to the University using the customary route, and parked where Gerry would park on Saturday evenings. There, standing in the dark outside the usual entrance to Gerry's building, was a slightly forlorn figure. Andrew must have walked the whole distance along an arterial road, crossing at least five major intersections, and with no sidewalk for about 2.5 kilometres. All these thoughts were in Elizabeth's mind. But, having learned that calm reassurance works best, she did not berate Andrew for the anxiety he had caused. She approached him gently and praised him calmly for having chosen such a sensible place to wait to be found! Andrew's family has still not worked out all the meanings of this adventure!

Angus lived with the Bloomfields for three years. He turned 15 and was now slowing down. His back legs became increasingly weaker. Soon he could no longer walk without pain. His appetite decreased; he could not enjoy his food. He was found to have cancer. The heartbreaking decision came in April 1990--Angus must leave them. The house felt very empty. Vickie cried for a week, while Andrew was obviously sad and missing his dog. Yet even without his friend, Andrew continued his regular walks whenever he was at home.

Another year passed. Vickie continued to miss her furry friend and insisted that life was incomplete without a family dog. Andrew had just returned home in distress from the failures of the group home placement and the experiments with medication. Vickie urged that he could benefit from the discipline and joys of caring again for a pet. Elizabeth and Gerry agreed and advertised in the *Globe and Mail* personals for a gentle, trained two-year-old golden retriever.

The eagerly awaited phone call came on the Victoria Day weekend. Gerry took the message. A two-year-old Golden Retriever, "an obedience school dropout" named Zachary, needed a new home. Several days later Zachary and his

owner came to visit. Zach was hyperactive, a bit overweight and very energetic. His owner was very sad that she could no longer keep him, as she lived in a high-rise apartment and worked long shifts at a hospital. She liked the idea that her dog would provide pet therapy for Andrew. She was impressed by Vickie's photo album of Angus, with pictures of him sleeping on her bed. She decided then and there to give Zach to the Bloomfields to be Andrew's dog.

And so a gorgeous and loving dog joined the Bloomfield household, to be much loved by all. He had only his collar and lead, so Elizabeth dashed out for supplies. That evening, she and Andrew led Zach for his first long walk in the University of Guelph Arboretum. For the next 24 hours, Zach was excited and probably rather anxious about the big change in his life. He hardly slept as he explored the house. Vickie and Gerry anxiously wondered whether the family could manage this super-energetic dog as well as hyper Andrew!

A few days went by and Zach did settle in, quite happily. Over the next few years Andrew learned to lead the dog by himself. Zach behaved better with Andrew than with the other family members. He is sensitive to Andrew's moods. As for other dogs encountered in the community, after seven years of walking around streets and parks with Zach, Andrew hardly reacts now when he meets them. His fear of dogs no longer limits his activities. Without the worry of meeting a canine at every corner, shopping centre and park, Andrew enters more fully into the life of the community. Andrew and Zach are close. Zach is the stimulus that gets Andrew going each day. Together they relax and listen to classical music. Andrew is especially happy when Zach can go along on outings and trips. Vickie's work in pet therapy, which gave her so much joy, lives on in the freedom Andrew now feels in moving about his neighbourhood and community.

In late 1998, Zach is still his daily companion and for the past year has lived with Andrew in his own house. This is very close to a riverside park which is ideal for walks, at least twice daily, and for meeting many other dogs and their owners. Andrew leads Zach calmly and responsibly, even when some of the dogs they meet may be off their leashes and rather exuberant. Andrew's regular walks with Zach in his new neighbourhood have been observed. He has been asked to be block captain for the Neighbourhood Watch, his duties including keeping an eye on more than 70 houses within a half-kilometre radius.

As Zach ages and nears a well-deserved retirement, there are plans for a guide dog, specially trained by National Service Dogs, to take his place as Andrew's companion.

7 LISTENING TO ANDREW

Andrew does not normally vocalize, though he spoke some words and phrases before he was five. He can greet friends with a "hi!" and to each table grace he adds his own "amen." At times he will utter strings of sounds that resemble sentences; he may seem to have two voices, using one while he gestures with one hand, the other with the other hand, as if he were holding a discussion with himself. Andrew vocalized this way a great deal after Vickie's death. He may use his voice in such a way when he seems both very happy and very upset. Staff at MRC and others used to say that they heard Andrew say things in these "voices" that are meaningful and relevant. When asked about why he does not speak, Andrew says it hurts his throat.

Andrew's life has been profoundly restricted by not speaking. He is remarkably good at receptive language, and at picking up the tone and "subtext" of what is said around him. He may understand what others are saying, but how is he to make *his* meaning understood by others? Put in plain terms, most people assume that someone who does not speak (or speaks haltingly) is "dumb" in every sense. Andrew has put much effort into learning alternative systems of communication. After the early years of behaviour modification techniques to induce him to utter basic sounds, the emphasis shifted to sign language from when he was six. But because so few of his support workers or friends have understood signs, he seldom initiates most of the 2,000 or more Signed English signs that he learned as a child. He will sign if he knows that the other person understands, and apparently remembers hundreds of signs, despite the infrequent use. He has always used gestures and pulls people in a desired direction to get his meaning across to those who do not know how to sign. Andrew says that facilitated communicating, to which he was introduced in 1991, is for him the best way he expresses his real meaning.

What is facilitated communicating (FC)? How does it work? It is an alternative mode of communication, first developed by Rosemary Crossley and her colleagues at the Dignity Through Education and Language Communication Centre (DEAL) in Melbourne, Australia. Douglas Biklen, a professor at Syracuse University in the state of New York, brought the method to the United States. The system of communication may involve the use of a small electronic typing device with voice and/or printed output, or just a simple sheet of card with the alphabet and numerals set out on it. The nonverbal person types on this answers to questions asked by a facilitator who lightly supports the person's typing hand, or by places a hand on his/her shoulder or back as he/she types.

Martha Leary of Toronto introduced Andrew to FC in June 1991. Susan Honeyman, another specialist and friend, has continued to give Andrew and his

family support and encouragement around all forms of communication. While she was alive, Vickie was his primary facilitator and Elizabeth was his discussant. Several tutors and one staff member at Midwestern have also acted as facilitators. Since November 1992 Andrew has used mainly an Epson keyboard computer. It has a voice output (male) as well as a display and printed output. Shelley Deegan of the Chedoke Technology Access Clinic (TAC) introduced Andrew to this equipment.

Andrew is a genuine user of FC. With it he is able to impart information and express his feelings while knowing that those who support and believe in him understand what he has to say. He types correct or relevant answers to questions asked. He also imparts personal information and general knowledge not known to his facilitator.

It was during his first use of FC that his parents knew that Andrew called them Gerry and Elizabeth rather than Daddy and Mummy. They had known for years that he thought of himself in the third person, beginning statements and requests with "Andrew Bloomfield..." rather than "I..."

It was through FC on the Epson that Andrew told his family in February 1996 that the drug being given to him at the institution was wrong and the cause of his restless, noisy, upset behaviour. He typed, "Andrew Bloomfield is very upset" and "Medication is wrong". Then, "PRN [medication given to quiet him] yesterday scrambles brain". Vickie, who was facilitating when Andrew typed these statements, did not know that he had been given two PRN doses the previous day! After another prolonged period of medication later in 1996, Andrew remarked that he did not know why he was given drugs. They seemed to be a punishment, as staff told him he was "bad" to be "noisy" and to "run," which he couldn't help when he felt "noisy inside." The drugs made him feel much worse, giving him severe headaches and tight feelings in his chest. As he had explained ever since he began using FC, what helped when he felt hyper were cold facecloths, classical music, being able to run a bit, quiet talking with friends, and trying to keep to his regular timetable.

Andrew loved using FC for general knowledge games, such as Brainquest and Trivial Pursuit. Geography, history, technology and ecology especially interested him. Sometimes, his facilitator might have another answer in mind, but Andrew would type the correct one. When playing these games with his family, after lunch and dinner at weekends, the set question might prompt further discussion and impromptu questions. Andrew's consistent answers and comments with FC showed that he really understood the information and loved the interaction. A few geography examples were:

- What European city means dam on the Amstel? (Amsterdam)
- What U.S. state's name is an anagram for Ha! I do? (Idaho)

- In what river do Hindus place bodies or ashes? (Ganges).

When a friend did not know the capital of Turkey, Andrew typed out one answer: Constantinople (the former name of Istanbul).

Family members might take off from the Amsterdam response to ask about the name of its country, and the people Andrew knew who had come to Canada from the Netherlands.

Andrew had political interests, it was learned, when he conjectured the outcome of the Canadian federal election in 1993. He said that a Liberal minority government would be elected and that the NDP would not do well because of the current unpopularity of Bob Rae in Ontario. He used FC to vote in the 1997 federal election.

Andrew's family had known for years that he seemed to like listening to their lively conversations and to enjoy humour and irony. Among all the books that he enjoyed in his family's home, dictionaries were among his favourites. Now it seemed that he wanted to use some of the longer words and liked discovering synonyms with slight but specific variations in meaning. The first time he took his Epson to Midwestern Regional Centre (so that it would be on hand for the rare occasions that a staff person might support him to use it), Elizabeth asked him what he thought about having his computer at MRC. He immediately typed "Sophisticated."

By 1993 FC was not only helping those around Andrew to discover his inner thoughts, needs and feelings; it was also helping him to enjoy trips in a widening community. Andrew's interests and growing emotional self-control were seen when in October 1993 he entered a restaurant to have a snack, for the first time in two years. The donut shop in Tottenham had other clients enjoying their coffee and donuts. Andrew sat with his family and calmly enjoyed his own snack. Later that afternoon they were unable to board a steam train as it was sold out. They returned to the car and Andrew seemed to be accepting the situation. However, he took out his Epson and typed: "Andrew Bloomfield feels angry. Want to ride train. Go for 4 o'clock train." He also added: "Andrew Bloomfield felt happy at going to restaurant." A lengthy wait and delay once on the train followed; Andrew remained calm and patient. Later he typed: "Andrew Bloomfield feels happy."

Through FC Andrew showed his family that he had an interest in academics. He wanted to go to university, to study Math, History, Geography and English. He liked to learn and read, he told them, and further impressed on them that he was smart. With FC Andrew could be involved in family decision-making. He could order menus of things he liked to eat, such as roast beef, apple pie, or turkey dinner at Christmas. Regarding Christmas, he requested that his presents be a surprise. Messages were typed to friends to mark the holiday season.

By 1994, Andrew was expressing desires to interact with more friends and to go on more outings. The previous year, he met with his FC penpal Elsie at a friend's farm near Guelph. With her Canon and his Epson they asked each other questions. Andrew asked Elsie about her sister and where she was; did Elsie like to sing; what types of grapes she preferred, red or green; asked why she chewed her hand and wondered if she was sad; was she going to have her lunch at home. Elsie had her own questions for Andrew, too. Why did he tidy things up all the time? Why wasn't he allowed to have many chips? To the latter question Andrew replied, "Eat too much and bothers me." They discussed the use of their machines, noting that Andrew's Epson could type and talk. Andrew wondered why Elsie could use abbreviations/ first letters when he was not allowed to. Andrew expressed his appreciation to his friend for the snack provided. He particularly liked the green grapes. Then, with humour and thoughtfulness Andrew said that Zach, his dog, hadn't come because he might scare Elsie.

The following weekend Andrew brought his dog when he again met with Elsie. This time he asked Elsie about what sort of work she did; did she go to school? He also asked whether she biked. He had two bikes at home, he told her. Elsie asked Andrew about his resistance to new clothes and maybe she could help. She also wanted to know about his use of his Epson to order meals in restaurants. Andrew replied, "Don't go to restaurants. Vickie brings me treats." But then he added that he could use his Epson going through the "Drive-thru" at McDonalds or Tim Hortons. Andrew told Elsie he was reluctant to use two hands for FC, as she did, because he feared he would make mistakes and type too slowly.

On August 30, 1993 Andrew was asked to demonstrate his FC to 30 special education teachers at a PDD conference at Chedoke Hospital in Hamilton. He was happy and honoured to assist his friends Honeyman and Karen, and his presentation was videotaped. His best friend Vickie accompanied him. FC, he told those assembled, was useful to order menus at home. Things he liked included Vickie's car, friends, books and trains. Noise, humidity, smelly things such as perfumes and food, when he felt "noisy inside" bothered him. When feeling upset, cold cloths, classical music and soft voices were helpful. He recalled that the first time he used FC, in 1991, he was feeling upset, but that he liked the animal books that his friend Martha Leary had brought. Andrew told the group that he had learned to read when "little - before school and P.A. (his teacher), reading books with Mum."

At this presentation Andrew told a joke. When asked who he facilitated with, he replied: "Jacquie, Ruth, Vickie, Zach, Karen." Did his dog really do FC with him, he was asked. He answered, "No -funny - joke". Perhaps Andrew's deep feelings about FC are revealed in his statement to the group that before FC he felt isolated, "retarded" and had no friends, and that sign language was not adequate.

On his Epson Andrew has expressed how he felt about the different months of the year, for his moods were affected by conditions in the various seasons. November was a difficult month because it is grey. May was his favourite with his birthday and he liked spring as it was warmer than winter. July and August were good months as he could go swimming with his friends, and these were the times that he took trips with Vickie. Midsummer heat could be very hard for him, but he could manage it with air conditioning. December was cold but okay with Christmas. January and February are also cold but he liked winter sports like skiing and skating, though dressing up warmly was not a favourite activity, for sure!

To help the whole family understand and manage his moods, in 1995 while he was home from MRC on weekends, Andrew and his family devised a ten-point scale so he can explain his mood. Numbers range from 5 (most equable) to lows near zero or hyperactive near 10.

0 -- "catatonic", unable to move

1-2 -- rather slow and apathetic, finds it challenging to do regular activities

3-4 -- well behaved, just a bit slow and tentative, needs prompting such as with slight touch on elbow

5 -- absolutely excellent, calm relaxed, wonderful

6-7-- calm, good but mild tendency to be excited, finds hard to sleep

8 -- rather hyperactive, finds it very hard to relax

9-10 -- totally wired, unable to concentrate, too hyper to be in community

They also devised codes for how Andrew handled his moods.

E stands for Excellent Effort, times when something may be bothering Andrew but he is not letting it get in the way (e.g. his fussy or picky ways are not interfering with work or other activities).

S stands for So-So/Satisfactory, when Andrew is having some trouble controlling his mood but is still trying, so needs extra patience himself and in his friends.

D stands for Difficult, when Andrew may be in the midst of a deep depression or state of hyperactivity and cannot control how he feels.

Andrew has had increasingly fewer times of "D for Difficulty" since he has been home and in his own community. Regular structure, no more "stop-and-go" changes each week, and access to communication through FC have made his life better. He is living proof that human beings have the ability to grow, mature and change throughout all of life--with the right encouragement, trust AND opportunity to communicate. At the end of 1995, supported by Vickie and Elizabeth, Andrew described the value of FC for him. Andrew and Vickie were on the program to demonstrate their use of FC at a conference at Syracuse University in May 1996. It was the last engagement planned in Vickie's diary, and was cancelled after her death.

WHAT USE IS FC ?

I was diagnosed with "classic autism" when I was nearly five and am now 27. I have used FC since June 1991. For the past three years, I have had an Epson computer with voice output, display and simple printer. I have also used a letterboard, Canon communicator and typewriter, but prefer the Epson because its voice helps other people to understand my messages.

For a long time, people close to me have known that I can understand what is said around me. The problem was that I had no way to get MY meaning and need across to other people. I felt really mad about this. When I was 6, I learned Signed English, I knew about 2000 signs and the staff at my special school called me their "sign dictionary." But signing was not good enough for me to express what I really meant and wanted. Sometimes I would sign "No" when I really meant "Yes" and people did not give me a second chance. It was hard to start the hand movements for signing, without being prompted by a question. When I did manage to initiate signs, too few people in the community understood sign language for it to be useful. I used to speak some words before I was 5, but then some specialists tested me and decided that sign language would be more efficient than trying to speak. Before I went to school, I learned to read when [my mother] read books to me. But at school, because I did not speak, everyone thought I was dumb in every way, so nobody gave me books to read or asked me questions. I kept on reading books at home.

FC has been good to me in several ways. I first used it when I was very upset and mad at the world. At last, I could express myself in ways that people understand. I could tell them what was upsetting me and what kinds of things help when I feel sad or angry. I am glad that, through FC, people know that I am smart. Some very good friends facilitate with me and help me by believing in me. During the past 18 months, I have been able to take trips away to other cities and stay in hotels with my twin sister, and nobody knows I am different... Only through FC can I express my real meaning clearly...

In early 1996 Andrew's FC suffered a twofold blow. Not only did he lose Vickie who was his primary facilitator among her many roles for him. But he also lost the expert and emotional support of communication specialists. FC users in Ontario have not been able to get professional help with this modality because of a ruling against supporting its use by the college or association to which speech pathologists and communication specialists belong. This ruling followed a court challenge prompted by one young man's alleging with FC that his father had abused him. Because of publicity about this case, Ontario agency managers and government officials have turned against any official funding or support for FC,

regardless of whether it works for particular individuals who may have no other means of communication. Similar cases in the United States and elsewhere (in which about half the allegations have been sustained in court), have been met with less drastic reactions than in Ontario. Andrew was profoundly saddened by this experience, as he insists "FC is real" for him. Physical contact with the facilitator symbolizes emotional support and the confidence of others that he does think and has something to say, though he does not speak.

Andrew's setback with FC (and his earlier experiences) form part of a larger and more pervasive phenomenon. A study sponsored by the Joseph Rowntree Foundation in England has found that "silent" children and adults who cannot speak are being routinely neglected because care workers assume that they are unable to communicate and overlook their various non-verbal abilities. Worse, social workers, care staff and their managers assume that people who cannot talk have no right to express choices. Some staff may go through the pretence of consulting their non-verbal charges in order to justify what they themselves find convenient. The 1998 report by Dr Jenny Murray recommends that independent advocates, with specialist communication skills, be appointed for each disabled child or young adult, so that their needs and choices can be validated.

In supporting Andrew to have a life of his own in his home community, his parents and friends know that he needs better ways of understanding and being understood. Since mid-1996, they have been developing a multi-modal approach, encouraging every possible medium of communications. On the one hand, Andrew's powers of receptive language are being stimulated to increase his functional vocabulary and range of experience. Social stories help Andrew know what to expect in new situations and experiences and how he may have choices and a sense of control.

For Andrew's expressive language, a social dictionary is being compiled to help the people close to him know the various ways he communicates. He needs FC to express things that are important to him, deeper concerns and needs than the choices of activities that may be adequately expressed in other modalities. He continues to use FC on a computer device. The Epson which has served him well for six years may soon be replaced by a more sophisticated and compact device, also with a male voice. Andrew is being encouraged to use the Signed English that he learned so well more than 20 years ago, for basic communication of his needs and wishes around the house and in his immediate neighbourhood. A new videotape, *Listening to Andrew*, has just been made of the 80 or so common signs that Andrew uses in his everyday life—those that he will initiate or use to make choices. People who share Andrew's house or his life should be able to recognize and respond to these basic signs. Newer for Andrew is the system of Picture Communication Symbols, stylized pictures that can be used as cues in a multi-

stage sequence of actions or as a basis of choosing among items and activities. He can also fairly reliably choose among several choices printed on slips of paper.

Teresa Pynenburg, who became Andrew's tutor in August 1997, set out to develop his interest in language and communication. Appreciating his interest in words, she encouraged him to increase his vocabulary by choosing, defining and using meaningfully more complex words that refer to activities and priorities that are important to him. She and then Andrew himself typed words, definitions and examples of use, as in the following:

WORD - Create/Creativity

DEFINITION - to bring into being; to make by applying the some artistic technique

EXAMPLE - I can express my creativity on the Epson as I expand my vocabulary

WORD - Artisan/Artist

DEFINITION - a) trained craftsman; b) a person who uses deliberate skill in making things of beauty

EXAMPLE - Andrew proves to be a terrific artist as he employs various mediums such as steelwork, gardening and puzzles

WORD - Invigorate/Invigorating

DEFINITION - to fill with power (physical or intellectual), enliven

EXAMPLE - Walks with Elizabeth and Zach in Riverside Park are always invigorating

Andrew's first major project in copy-typing skills involved compiling a bibliography of books about autism and other disabilities. After a little step-by-step guidance, he was able to transcribe details of title, author, year of publication, and a brief abstract of the work from the books themselves. It had been assumed previously that he could recognize only printed capital letters. The discovery that he could decipher the fancy fonts and layouts of book cover designs and type the salient details in appropriate upper and lower case was one of the miracles of late 1997. Another was the pleasure he found in working on the computer, which he said he wanted to do for three hours every day.

These discoveries prompted the idea that Andrew's communication skills could be further stimulated and used by having a better computer of his own. With Teresa's help, he wrote that story himself for the Fall 1998 newsletter, *Adult Autism Issues in Waterloo-Wellington*.

This past May, I was very fortunate to receive a Victoria Bloomfield bursary. As it is very important to me to increase my communication as well as

work and learning possibilities, my family and I had decided to ask for a bursary to help towards the purchase of a new Pentium computer.

I started working on a computer in a formal way in October 1997, when the president of the Wellington County Chapter of Autism Society of Ontario asked me if I would help compose a bibliography of his library of books about autism and other challenges. This Bibliography list would help families and other interested people to find information they need to learn more. Prior to this I typed a few messages, vocabulary lists my tutor coached me with, and an excerpt from National Geographic. I have been familiar with the QWERTY keyboard since 1987, when I began doing some educational computer games. In 1992, for Facilitated Communicating, I started to use an Epson computer, which also incorporates this style of keyboard.

The computer I was using until this past spring was more than 10 years old and I learned a bit about Word Perfect 5.0 software. When I first had the new Pentium set up in my living room, I spent some time working on each computer, as a transition and comparison. I then felt comfortable with the look and feel of the new hardware and software that include: a mouse, CD-ROM, colour printer and scanner. My computer also features a lot of software such as Microsoft Office (mainly for word processing projects), Pagekeeper (for scanning), access to the Internet, Encarta Encyclopedia and Reference CD and Boardmaker.

The Boardmaker software is particularly important and useful because through its expansive dictionary of word picture symbols I can achieve three significant goals: learning, communication and work. My tutor says the first thing I have learned using this software is alternating using the keyboard and the mouse. The mouse is a new concept for me and I still have to practice matching my movement of the mouse on the pad to the arrow/cursor on the screen. I am also learning about all the different ways I can expand on my multi-modal communication abilities by creating graphics I use in my everyday life like prompts, schedules and choices of activities. I like the feeling of independence this gives me.

My computer is a tool towards my goal of long-term work that helps people. Supported by my family and friends, I am starting my own small business called ABCommunications. The main function of my job would be designing Picture Communication Symbols for others with communication challenges (i.e. picture communication boards/ schedules that may include lamination and/or velcro). In addition to creating these communication aids and devices, I also provide collating and copy-typing services. I have done collating work on a volunteer basis for several years, most recently a job assembling packages for 840 high schools across Ontario for the University of Guelph. Since the beginning of this year, my copy-typing work on computer has included a 150-page document for the Credit

Valley Conservation Authority and a philosophy paper for a University professor. For future requests for collating jobs, such as assembling newsletters for distribution, a mailing list of 100-300 people is an appropriate length for me.

I have a lot of energy for work, exercise and shared experiences with family and friends. Because variety and balance are important in my daily schedule, I see computer work and ABCommunications as an important complement to other parts of my life such as taking care of my house and being out in the community. I am grateful for the bursary and all the opportunities it gives to improve the quality of life for me for people of all ages for whom I can do work.

Communication, widely defined, becomes even more important in implementing Andrew's exemplary person-centred and self-directed plan. His family and friends have resolved to do their best to ensure that he understands his options and that others really are "listening" to hear his priorities and preferences and whether he is bothered and unhappy about anything. His multi-modal communications strategy depends on the co-operation of others to be effective. Some people find that one medium or mode suits them better than others. Andrew is very tolerant, being on the whole grateful for any effort to "listen" to him. He is apt to become frustrated and/or withdrawn if his companions cannot understand any of his systems.

The development of Andrew's intellectual potential and his practical skills on the computer illustrate the fact that, regardless of age or handicap, the human being is capable of growing, changing and creating. Andrew has said that having autism is like being a horse locked in a barn but desiring to be out in the field where it can run and be free. Andrew knows he is autistic but he has the curiosity and desire to learn and explore the world around and beyond him. Vickie opened those first windows for him. His family, his friends and his home continue to support his future with all its dreams and plans.

8 *EXPLORING THE WORLD WITH FRIENDS*

Andrew wants to be by himself. Or so it was thought for many years. His autism had cut him off from other people and it was assumed that he did not care much for people and that he preferred his own company. It was when he began to use FC that it became very clear that this assumption is a myth. "Friends"--people who have empathy and understand him--are vitally important in giving meaning and fulfilment to Andrew's life. They also help him to cope through times of mood swings including deep depression. With this revelation Vickie especially brought social experiences into her brother's life during the first half of the 1990s.

Andrew uses "friends" and "community" to mean a whole range of social contacts and experiences that are very important to him. However he cannot take the initiative or follow through the steps to make and keep friends. Vickie, as he clearly said, became his "window to the community," interpreting, facilitating and orchestrating his social experiences during weekends and holidays which were his breaks from the institution at which he spent most weekdays.

Once Vickie had her car, from August 1991, she took up all opportunities to visit friends in their homes and to make new social contacts of all kinds. Good friends were also invited to come to his home. As with his family since he was little, Andrew enjoyed playing card games, Tri-ominoes and dominoes, and doing puzzles with friends. Skating at the University of Guelph became a happy shared pastime with some new student friends in 1994. Bowling and horseback-riding were further activities, as were regular visits to public libraries to read magazines and borrow books and tapes. There were also occasional visits to church for special music services, especially at the church of his friends Ruth and Monica.

Vickie believed in Andrew. With her empathy and use of FC, they began longer trips together. Sometimes Zachary went along too. They were able to travel considerable distances, stay overnight in hotels and eat in simple restaurants. In all their travelling there was only one incident, and that was overcome so the trip could continue. Of all that Vickie gave Andrew in her last five years, her companionship and support in exploring the community and the wider world was the most heroic and remarkable. Through these experiences, she extended his range of interests and proved his desire to share activities with his age peers and his ability to continue learning.

This book about her twin was Vickie's idea and inspiration. She recorded stories about Andrew's and her trips to various places in Ontario and also to the U.S. This chapter includes her accounts of five of the trips they made in her last summer and fall. In July 1995, they visited Greenfield Village in Detroit, Michigan for the second time, having previously gone there in 1994.

Andrew and I had a splendid trip to Windsor and Detroit over the weekend. We visited bowling alleys, dined in restaurants (McDonalds for frozen yogurts; Tim Hortons for sandwiches, Wendy's for salads) and slept in hotels. It was a delightful change and holiday for both of us. The highlight of the trip of course was going to Greenfield Village in Detroit... It turned out to be the most perfect day to visit the village as it was warm and sunny and because it was a special weekend where American Colonial life was being featured. There were special exhibits on Colonial domestic life --cooking, clothing, candlemaking, storytelling, as well as a woodland encampment and a non-denominational church service. The most exciting aspect was the Colonial military music. There was a grand entrance parade, a fife and drum muster and corps concerts as well a grand egress at the end of the day. Weapons demonstrations were also held during the day on the village green. The drum corps came from Sterling Heights and Plymouth, Michigan as well as Acton, Illinois and Delmar, NY.

Thus Saturday at Greenfield began with grand stirring American bands, followed by a ride in a 1931 Model AA Bus shuttle... This bus gave us a tour of the entire village for 25 cents. Apparently it had been used in the 1930s to deliver rural children to school in Kentucky. We then went to look at parts of Greenfield Village... These included looking at the Firestone Farmhouse and Barn of 1828 which are typical Pennsylvania German building types. A calf, rams, roosters and a ginger cat inhabited the barn. The William Ford barn had horses in the stalls, which are used for the wagon rides and carriage tours. Andrew and I then went to see the work demonstration centres - including the pottery shop, textiles and glass works. Andrew participated in a print shop exercise, making a postcard of the Suwanee Steamboat. We also looked at the modernization of the lumber industry, seeing an up and down sawmill, that was later replaced by a circular sawmill. We also saw a demonstration of silk making at Hanks Silk Mill (1810).

We then had a tour of buildings of the mid-nineteenth century that are featured at Greenfield, including a Stationmaster's house and railway depot of 1858, a post office of 1825, jewellery store of 1880s, a general store, doctor's office and houses of famous people like Stephen Foster's (who composed "O Susannah" in 1830) and Noah Webster's house from New Haven, Connecticut (1823). He compiled The American Dictionary of English Language. It was considered an upper-middle-class home in its time but is very grand in terms of size for today! We enjoyed a picnic lunch of fruit, vegetables, nuts, juice and popcorn at the Suwanee Park, followed by a ride on the 1913 Carousel, complete with organ music n the Wurlitzer organ built in North Tonawanda, NY. The carousel had been used at Liberty Lake, near Spokane, Washington from 1923 to the 1950s. The carousel was so popular that we had to wait several turns before

we could go on; but the music was so lovely that we did not mind and Andrew was extremely happy.

We went on to look at other parts of the village, including the Cotswold Cottage and forge of the 1620s, a Cape Cod windmill and a slave plantation of the 1840s. The Susquehanna plantation had the grand home of slave owners as well as the dairy house where slaves made butter and cheese as well as a wheat field and tobacco field. Apparently by the 1840s, it was becoming more profitable to grow wheat than tobacco and it was less labour intensive and less destructive to the soil.

Greenfield also has the Ackley Covered Bridge (1832) from southwest Pennsylvania and the Wright brother's home and cycle shop of the 1890s from Dayton, Ohio. Not only does it have Henry Ford's birthplace and his Mack Avenue workshop of 1903-1905, where Ford had a small assembly operation. There is also Thomas Edison's Menlo Park Laboratory of the 1880s--one of the most popular exhibits, and Edison's winter workshop, which he used between 1885 and 1920 for inventions like synthetic rubber. Across the way is the Sarah Jordan Boarding House, where his female workers boarded. After this fantastic tour of the village, we finished off with a ride on the Greenfield Village railroad - a train pulled by a steam-powered locomotive. At the end of this, while we were enjoying a snack break, the military band marched past. We then looked at the village gift shop and found cranberry jelly and educational card games about famous American women and historical figures. Thus our trip was both educational and informative for both of us, as well as being fun and relaxing. Andrew said later that he was a happy guy!

Andrew and I also enjoyed bowling in Windsor. We went 5 pin bowling on Friday night - Vickie won. The next evening we had two games of 10 pin bowling - the first game we tied, then Andrew was the champion. Andrew was really well-behaved throughout the whole trip and a delightful travelling companion.

Andrew's and Vickie's next excursion, to Ohio and Bittersweet Farms, took place August 6 and 7, 1995. In late April 1993, Elizabeth and Gerry had visited Bittersweet in order to gather information on effective service models for adults with autism. A farm community for autistic adults located 20 miles southwest of Toledo, Bittersweet was established in 1983, after ten years of planning and intensive efforts to get going. Bittersweet is the name of a native vine, but the word also resonates for people concerned with autism.

When Elizabeth and Gerry visited Bittersweet in 1993, 20 adults were living in the farm community, and 10 others came in each day. All functioning levels were represented. One mechanical genius ran her own repair business, then later had a daytime competitive job away from the farm. The Bittersweet program interacted with the local and wider communities. During the summer and fall, a

roadside teahouse offered refreshments and various goods made on the farm. On major open days three times a year, up to 2,000 visitors come to share in special events.

In a letter to her grandfather in England, Vickie describes Andrew's and her visit to Bittersweet Farms. Her letter also gives us a glimpse into the life and specific activities of the members of the Bloomfield household at this time. The twins' grandmother had died a few weeks before Vickie's letter, and the family had extended an invitation to Gerry's father to come to Canada and live with them in Guelph. "Grandfather" visited Guelph for six weeks in September-October 1995, but eventually decided that it was best for him to remain in England in a more familiar environment.

Dear Grandfather,

We are all very excited at the prospect of your coming to stay with us this fall to see if you like Canada and whether you might like to live with our active family. Andrew has said "Andrew Bloomfield would like Grandfather to come" and we all agree!

Gerry and Elizabeth had a rare day out on August 3rd - they went to the Blyth Festival to see The Tomorrow Box. This is a modern Canadian play that looks at family survival strategies. They reported that it was an attractive theatre of about 300 seats - and full with largely an older audience. However the themes in the play really resonated with the audience and they enjoyed it immensely. Blyth also has a superior store that sells wool blankets and sheepskins, so some special new items were purchased for the house. Meanwhile Vickie researched the buying of coffee grinders and cappuccino makers for the coffee lovers of the household.

Gerry has just finished the final corrections to his course handbooks for the fall and has been planning the lecture schedule and activities. Vickie is also starting to think about these things for her course at McMaster. Elizabeth's book is in the final stage of production - it is all in the hands of the printers now! The book will be launched in Kitchener on Saturday October 28. That day Vickie will present her paper on Decentralization of Industry in Toronto during World War Two at a conference at York University.

A and V had a second fantastic trip to the United States during the first weekend in August. Andrew had expressed a desire, using FC, to visit Bittersweet Farm, a special program for adults with autism. Gerry and Elizabeth had visited the program in 1993 and brought back a videotape of the farm. It is located on the edge of Toledo, Ohio, so Andrew and Vickie stayed in a Hampton Inn on the Maumee commercial strip.

The weather was warm that weekend so A and V kept changing their minds as to whether to go but Sunday morning dawned cool, so they set off - first to 5 pin

bowling - they each won a game -and then westwards on the 401. Andrew was exemplary - he enjoyed visiting restaurants such as Wendy's, McDonalds and Tim Hortons and was very patient on the long stretches of freeway driving--the 401 and the I-75 through Michigan and Ohio. Andrew enjoyed playing card games after each break as a change from being confined in the car. A and V reached the border crossing (the Ambassador Bridge at Windsor) at a rush hour, 4:30 pm. It seemed as though many Americans were returning home after gambling in the Windsor casinos.

We enjoyed exploring new territory, as neither of us had been south of Detroit before. The Maumee commercial strip not only had the fabulous hotel and a good Wendy's restaurant (home of green salads) but also had a huge bowling alley! Southwyck Lanes offered 10 pin bowling. Toledo we learned is a great bowling centre and holds many tournaments; it has at least 60 lanes. Only half the lanes were in operation on a Sunday night and no bumpers were available. Thus bowling was more of a challenge than usual. Andrew however soon developed a good technique and won all 3 and a half games. (It was cheaper to pay \$8 US for an hour than pay \$2.25 US per game - it would have cost c.\$16 otherwise).

Andrew used facilitated communication throughout the trip to express his feelings and preferences. He indicated what he wanted for breakfast (toast with peanut butter, apple juice, muffin and tea); that he felt hot and a cold cloth helped and that he liked the trip. A and V had hotel rooms on separate floors. Andrew was sound asleep at 11 pm when V checked and indicated the next morning that he had indeed slept well. After breakfast, FC and checking out of the hotel, the "two guys" proceeded to Bittersweet Farm, along Ohio route 64, near Whitehouse.

Our first impressions of Bittersweet Farm were impressive. Purposeful work was evident as we turned into this attractive 80 acre farm property (about 35 acres are woodland behind the farm). Young people were at work mowing the lawns and weeding the gardens. We met the director, Charlie Flowers who gave us a good tour of the farm. First we saw the kitchens, which prepare about 70 meals daily with both staff and clients working together. We then saw the weaving room and the art/music rooms, which are utilized more in the winter season.

Staff hired at Bittersweet are not merely special education trained but many are experts either in craft production - such as weaving or dried flowers or in animal husbandry or horticulture. Bittersweet grows produce for themselves and cultivates many flowers which are dried and offered for sale at harvest time and Christmas particularly. The horticulture program is the main stay of the income generation with delightful dried flower arrangements offered for sale as well as hanging baskets of animals and perennials. Three greenhouses are used to grow seedlings.

Bittersweet stresses productive work that is necessary, such as gardening, but is also natural and therapeutic. There are chickens that produce eggs, rabbits, goats and pigs as well as two work horses, Dolly and Molly, that plough the land. A developmental riding program is also in place - two horses, Bowinkle and Annie, are kept for this purpose. The farm program, which began in 1983, also does woodworking, making wooden patio furniture and other knickknacks. These products help generate revenue which can be used to buy the raw materials, such as seeds. All work is individual-centred and tailored to meet each person's needs.

39 adults are currently being served by the program. 20 live onsite, two in a 24-hour supervised apartment offsite and 17 come in for the day. Many of those coming in by day are paid for by the local school boards. During weekends, adults with autism do regular activities in the community like hiking, swimming, bowling etc. Bittersweet has a full-time speech pathologist and many clients are non-verbal - using pic symbols, FC, touch talkers or sign to communicate. We also had a tour of the Co-op home - where 5 of those at the farm reside. It had a glorious living room with fireplace and single rooms for all adults. Bittersweet employs about 75 workers (many are part-time; covering Mondays to Fridays 9-3).

Charlie was impressed by Andrew's demonstration of FC on his Epson. He asked Andrew how long he had been using FC and A responded 4 years. Andrew asked to look at the gardens, asked about kitchen work, said that he liked the farm and wanted to know about learning. Charlie indicated that there was little academic training at Bittersweet - the emphasis was mostly on vocational work skills. For those in the kitchen, for example, the goal is eventual restaurant work.

As to creating a Bittersweet North in Ontario, Charlie Flowers said that it was probably no longer feasible to get funding from one source but that elements of the program would have to be pieced together. He suggested that a non-traditional work program, such as horticulture therapy, could be justified as it increased personal freedom of the individual, could raise some money, and is natural, useful, labour-intensive work. He said that they have not written up the success of the program much; they are too busy actually doing the work program. Bittersweet appears to have more structure and variety of work than most programs for adults with autism.

Two main findings that emerge from the Bittersweet model are the importance of a concentrated work site with a variety of purposeful work, and the need for staff skilled in types of work being done--not just special education workers.

After this interesting visit, Andrew and Vickie went south to see the college town of Bowling Green [where the Journal of Cultural Geography had just published Vickie's article on Tim Horton's as a form of popular culture]. They looked at the State University there, had lunch as well as visiting a bookstore that

had a set of super BRAINQUEST questions on US geography. They then headed north again on the I-75 back to Canada to avoid the late afternoon rush. There was no problem returning to Canada – we were welcomed back! Vickie phoned Chatham and learned that the bowling alley there was closed for renovations. After talking it over, A and V decided not to stay in Chatham but to go home instead - visiting a restaurant en route. Andrew indicated that the money saved could be used for another holiday in late August, perhaps in Niagara. We shall send more pictures soon!

Our tomatoes are doing well - it is lovely to go out and select big ones for salads or baby ones for kebabs! We hope that our red cabbages will be ready soon. The weather has been pleasant this week - warm during the day but quite cool at night.

On August 20-21, 1995 Vickie engineered a trip to Niagara Falls and Niagara-On-The-Lake. Her goal was once more to give Andrew a holiday and community experience in a busy tourist spot. He would also look after Zach who would accompany them on this trip. Her record of the trip follows:

Andrew and Vickie had another splendid holiday in late August. Elizabeth suggested that Andrew might enjoy a special boat ride on the Maid of the Mist at Niagara Falls. Andrew was indeed very keen on the idea so Vickie scheduled this for a weekend when not much else was planned. The hotel rates in Niagara Falls vary considerably depending on the night of the week. On Saturday nights the rate is \$225 per person compared with \$150 on Fridays and a reasonable \$64 on Sundays. Therefore we decided to stay over on a Sunday night.

After a morning of photocopying and bowling followed by lunch and an afternoon walk, Andrew, Vickie and Zach set off for Niagara. The Niagara region is so attractive that they decided to take the dog along as well. It was also important to test how well A could cope with this. The Comfort Inn by the River takes pets and both A and Z were keen to go! It was a warm day but both coped well. They arrived in Niagara Falls and looked around at the Niagara Square Mall, the main commercial strip - Lundy's Lane and then found the excellent hotel near the Bridge to the U.S. by the old town of Suspension Bridge. The hotel was located in a quieter zone of the busy town with a view of the whirlpool and adjacent to lovely parkland. All enjoyed gorgeous walks in the area, around parks and the whirlpool rapids. Later, A and V enjoyed a lovely dinner at Wendy's and drove around the falls and the Niagara Parkway. Hundreds of tourists were there enjoying the falls but Andrew led the dog calmly! They viewed the falls at night--very dramatic.

All enjoyed the Comfort Inn - they had adjacent rooms on the ground floor and both A and Z behaved like seasoned pros! We highly recommend this friendly chain! Andrew took special responsibility for Zach - leading him on the walks and making sure he had lots of water to drink. On Monday, we walked Z early (meeting other friends with dogs at the hotel. One dog had visited 37 states in the U.S. and is a great traveller!). Then we set off on the Niagara Parks Commission "people mover" to the downtown to enjoy the Maid of the Mist boat ride. We had to wait for a long time as hundreds of others wanted to take it too. Andrew was extremely patient and enjoyed travelling right under the American and the Canadian (Horseshoe) Falls. We then drove north to the Niagara Botanic Gardens and gave Z a walk there. We then proceeded past Queenston's floral clock and the Sir Adam Beck Generating Station.

Niagara-on-the-Lake, our next destination, is quite a genteel contrast to the more "honky-tonk" Niagara Falls. It was also busy but not to the same degree! We stopped in Simcoe Park for a picnic lunch and then walked around the scenic town, shopping at Grieve's for preserves, and then walked Z again. We saw other attractions, such as a trolley bus ride, which Andrew said he would like to try on the next visit. Andrew said with FC on his Epson, that he was hot and would like to drive back to Guelph and "please on the way stop at McDonalds for a chocolate frozen yogurt cone". Vickie obeyed the "oracle" and a treat was enjoyed by both in St Catharines. They then took a special hike around the University of Guelph Arboretum before visiting Wendy's in Guelph for another special dinner out. Andrew said on FC that he enjoyed the trip very much and loved Vickie. Meanwhile, friends have been researching future trips for "the guys" to Ottawa, Peterborough and Kingston.

October rolled around and Andrew requested another holiday to celebrate the fall weather. He decided that he would like to visit Stratford and London this time and take the dog along, as he did to Niagara Falls over the summer. Accordingly, Vickie booked the "3 Musketeers" into the Comfort Inn in London for the night of October 8th. As she recorded the trip:

...Next morning, Andrew and Vickie went 5 pin bowling (V won both games) and then they picked up Zach and headed westward to Stratford. A Tim Hortons lunch was enjoyed by all and then they braved the elements for a cold walk around the river and houses in Stratford. They visited the special Stratford Festival bookshop and discovered some good educational games on Art and Shakespeare. They drove to London, had a snack and walked around St Julian Park. Then they settled into the hotel, with connecting rooms on the ground floor, which was very convenient. A trip to Wendys for dinner and a superb promenade along Pond Mill

Conservation Area trail were successful. During the evening, Andrew and Vickie played lots of games, including the new ones bought that afternoon and listened to lovely classical music. Andrew also did lots of FC, expressing his pleasure at having another holiday.

The next day, the three guys discovered another trail around Greenway Park for the morning walk and drove around the Storybook Gardens area. Certainly London offers possibilities for future visits and hikes and Andrew expressed interest in visiting again. Then they took a scenic drive to Listowel on Highway 23 through Mitchell and Andrew had a special muffin treat at Tim Hortons. He then led Zack around Midwestern Centre (where he resided during the week) and said that he would work hard during the coming week.

Andrew, Vickie and Zach had one more holiday trip that fall, on November 19-20, this time to Barrie and Camphill Village Ontario. Camphill is an international group of communities for disabled persons who are called villagers. Camphill Village Ontario is an intentional community on a 300-acre farm located between Angus and Barrie. The first Camphill community was developed in Scotland by World War Two refugees from Central Europe. Twenty villagers lived and worked in Camphill Ontario at the time of Vickie's and Andrew's visit, along with 20 non-disabled persons. Vickie describes the trip:

The three guys - Andrew, Vickie and Zach - set off for a special holiday to visit Camphill community near Barrie in mid-November. They went along scenic Highway 9 which has rolling hills. Given the early snow this year, it provided attractive winter views! They stopped at the drive-thru Tim Hortons at the intersection on Highway 9 and 50 for treats and then proceeded eastwards to Highway 400, which took them northwards to Barrie. Located at interchange 96 was their hotel, the Comfort Inn, which welcomes pets and has connecting rooms.

A small crisis arose when we went for a walk on the Barrie waterfront. Andrew, after being asked to straighten Zach's lead which was twisted around the dog, suddenly became violent and began whacking the dog. Vickie managed to separate the cowering dog and got a very upset Andrew down the road to a Burger King, where Andrew visited the washroom. An anxious time followed when Andrew disappeared. Vickie and Zach looked around the bus terminal and a street person told them that he had proceeded up the main street. Vickie got Zach back to the car and when driving along the waterfront, spotted a happy, relaxed guy strolling along....Andrew. This unforeseen event reminds us (a) that autism means the unexpected can happen anytime, anywhere; (b) that one can remain calm and not react in a crisis situation - it was dark, cold and in a strange city and can summon up reserves of strength!; (c) that Andrew can have a violent outburst, recover from

it and have a splendid holiday. In the past, this would not have been possible. Later he apologized for "getting mad" on Epson. Desperately needing to go to the washroom seemed to be the cause.

Andrew and Vickie then enjoyed a lovely dinner at Wendy's and then settled into the hotel. Andrew helped with Zach and did some collating work. Then they went 5 pin bowling at the Barrie Plaza. The first game was a tie with 118; then Andrew was the champion with 147 to 98! This alley was smaller than the Guelph Bowlerama and the scoring was not computerized. Andrew loved the continental breakfast offered by the hotel - cereal, bagel and cream cheese, fruit, juice and tea. Then the three guys set off westwards to Angus, Ontario where they looked around the community as well as Camp Borden military base which has a hospital, newspaper, parks, McDonalds and a military museum.

They arrived at Camphill Village about 10:15 a.m. and looked at Tamarack, the house where Sharon and family lived. Andrew used his Epson to tell Sharon how he likes her house for being light and airy: that he likes classical music and friends are important; he also likes bowling and "horses are wonderful". They then had a tour of the community, with Annette, aged 22 from nearby Tottenham, who also loves bowling and stamp collecting. She has been part of the community since September 1994. We saw the barn, the dairy, woodworking where Andrew again demonstrated FC. He told people that he was smart, 27, his favourite season was spring, that he liked to travel and had been to Niagara Falls and Ohio this year and likes work, particularly collating. Andrew and Vickie then viewed the bakeshop and the art room and visited the community centre to pick up an application form. They saw the village store and purchased Camphill maple syrup and a special compact Disc of Bach music recorded for Camphill. The storekeeper was charmed by Andrew and gave him some special nutritious potato chips and fruit candy.

Annette guided us to Algoma House where Diane Kyd and family live. Diane remembered meeting A and V ten years ago when they visited Camphill in its temporary location near Erin. Andrew again demonstrated his FC, saying how he liked Camphill people and the food; that his birthday was May 6th; that he might like to come and live at Camphill. He had a question: "Andrew Bloomfield wants to know how he can come here to live?" They said that he could come for a weekend visit, then perhaps a week, to see how it works out for all concerned. Apparently, the community is planning to build a new house next fall. Gerry and Elizabeth were warmly invited to come and visit in mid-December. Andrew was asked by Diane, who has used FC with others, how FC and the Epson have changed his life? Andrew responded: "Andrew Bloomfield is happier since Epson". He had "more choice" but that one problem is that he "needs more people to facilitate." All the people there were warm and welcoming, making us feel part of

an extended family. Andrew was charmed by them. He gave lots of happy grins and loved Diane's books. His eyes shone when he saw the wood fireplaces and pianos in the different houses. He also met others with challenges - Joey, aged 37 and his mother Ursula, and Terri who showed us her beautiful corner room.

Thus Andrew seemed to enjoy another trip very much. He smiled and chuckled all the way back to MRC, enjoying treats from the hotel and Camphill. Vickie drove through Tottenham (pointing out the South Simcoe Railway with its steam locomotive, which he could visit again sometime), as well as through the town of Alliston. This special trip was on top of a good weekend, where Andrew had also been 10 pin bowling after delivering Sears catalogues on a new route (to apartment buildings); doing office and collating work of Christmas letters; and making new friends like Giselle Rivest, who plays guitar and loves sports.

These stories, presented as Vickie wrote them, are not merely tales of interest; they offer profound sketches of a very special brother and sister. The potentials and abilities of Andrew come alive as he is given by Vickie the opportunity to experience the world around him. As I began to compile this book, I asked Andrew what he wanted included. On FC he quickly said, "Tell about Vickie". So much of Andrew's story is also Vickie's story, and in their shared times is seen a sibling who believed, trusted and gave all her energy, focus and insights into planning and fulfilling experiences that would enrich and enlarge Andrew's life. It was a time they planned, discovered, and enjoyed fully, not as a task or an experiment. In retrospect, their last months together were in human time, short, but the gift of her love and compassion, of who Vickie herself was, lives on! Their relationship can never end; the effects of Vickie's life on Andrew's continue. For he continues to study and learn, to have fun, to travel, and to work. Vickie set a high standard for Andrew's social experiences: may it continue to inspire his friends.

Since Vickie's death, Andrew's parents, tutors and friends have helped him to carry on some activities that give him social experiences. These good times have also been valuable as purposeful outlets for his abundant energy.

Part of the purpose of having his own house is that Andrew can invite his friends to visit him and to share some activities and interests. There is so much to do at home now that there is less time to travel far afield. Friends who visit Andrew's house may see jobs that need doing, and ways that Andrew can share in them.

Andrew enjoys and relates to people of all ages and interests who show that they understand and like him. He is sensitive to their moods, and will try to express comfort to someone who is sad or stressed by lightly touching her forearm and looking into his eyes. He takes a while to get used to any new person or experience, and is helped if his social experiences form part of a regular and

predictable timetable. Andrew counts paid support people as friends, too, and now has the power to choose who will have these roles.

Andrew's most constant friend is Marie who visits him at his house one evening each week, sometimes bringing her daughter Kate and other young friends. Kate's school speech about her friend Andrew was highly commended; it helped her classmates to understand how someone who does not speak can still be "smart" and interested in other people and the world. Usually they work together on a new jigsaw puzzle and listen to music, but may play board and table games, read stories or do a bit of homework together. Marie's family has invited Andrew to their place for swims and for dinner.

Some friends who have welcomed Andrew to their homes have also come in small groups to prepare and enjoy special dinners at his house. Andrew loves to share in food preparation, especially the tasks of cutting, mixing and stirring. He enjoys eating the food too, usually serving himself a modest first portion and then requesting a second helping with his eloquent signs for MORE PLEASE. He naturally assumes the role of host from his seat at the head of the table. He makes a very eager and efficient waiter, and is a competent partner with Gerry in the cleanup team.

Other friends have supported Andrew's exercise programs. Vince is a good friend who has accompanied Andrew for "gym and swim" at the University of Guelph Athletics Centre during the fall and winter semesters since November 1996. Kim and John also accompany Andrew to the gym and pool, and sometimes for snacks afterwards. Andrew went with them (and his new friend Mary Glennie) to the Hillside Festival at Guelph Lake in July 1998, when he also rode the bus and explored downtown Guelph with John.

To be able to enjoy leisure activities, Andrew needs the many people who in various ways bring purpose and meaning to his life. They are his circle of friends. One visits to talk and play dominoes, another picks him up for a game of bowling; or he goes with others to the Milton Steam Fair or to ride the new train from Waterloo to St Jacobs. His tutor takes him for occasional field trips--to her brothers' farms in Oxford County, or to the workplaces or headquarters of friends who have found work for Andrew to do. Andrew's own house is planned as a focal point for all his activities, including his relationships with his friends.

9 *REAL WORK*

People who live with challenges like Andrew's are not obvious candidates for real jobs. And some of their friends might say that they should not feel obliged to work. But Andrew does want to work and to be useful. His stamina, fine motor skills and hand-eye co-ordination lend themselves to many useful tasks. Without the structure that daily work provides, his days in group home or institution were empty and he felt bored and frustrated.

Using FC, Andrew has expressed his philosophy of work—most memorably in a conversation in mid-November 1994, with consistent confirmations ever since. He distinguishes “real work”—meaningful tasks that help others and/or which people take seriously enough to pay for—from “makework.” Asked how he had liked being in a vocational training program organized during the previous four months by Waterloo-Wellington Autism Services, he declared without prompting that “Work is worthwhile, very important.” The purposes of work for him were to “get paid, help others, and enjoy going into the community.” Money earned from work was needed to “pay for treats.” His favourite work was in a library, where he liked to put books away and photocopy; he liked libraries because they had books and were quiet places. He also liked feeding horses and general stable chores for Sunrise Equestrian Centre, and all forms of housework. It was fine to have a steady flow of collating work.

Asked how important it was to him to be paid for work, he replied: “Boring work must be paid” and gave examples of the work he found boring (not all of which he was paid for). Andrew said that he wanted to work one hour a day for pay, and six hours a day as a volunteer. He said he needed a lot of support and patience to learn the tasks of a new job. When he has learned a work skill, he never forgets it, but says that he still needs someone there—though that person could be doing something else. Since Andrew has become accustomed to computer work, it is now his favourite and he likes to spend 3 hours a day at his computer. He likes a balance of several kinds of work in a day and does best with short “body breaks” for 5 minutes every hour or so, to stretch his muscles and have a drink of water.

Andrew experienced several work skills through the years he was away from home for most weekdays but home during weekends. He became adept in flattening cardboard containers for recycling. He helped in a library and assembled headsets as part of an airline contract with Torchlight Industries. For a few weeks, he did well and was paid for a few weekend hours cleaning a campus pub at the University of Guelph. For about 20 years, he has done “collating” which is his shorthand for various tasks—sorting and folding pages, stuffing and sealing envelopes, affixing address labels and postage stamps, and wielding rubber stamps—involved in handling mailings for organizations or businesses.

People who work with Andrew are indebted to Vickie for good advice on effective strategies, as in so many other ways. Eight months after Vickie's death, Andrew had a two-hour FC session with professional friends, without either of his parents present. He said that he missed Vickie so much. She had "helped him to talk" and was "his best friend and wonderful sister." He missed her for games, outings and trips, but especially for how she trained and encouraged him in work skills. She was "tough on him" which meant that she set high standards, believed in him, and insisted that he did things properly. He stressed that this was very good to ensure that he learned "real work."

Vickie wrote up two model procedures that she developed to teach Andrew new work skills, in the hope that they might help others.

FEEDING HORSES AND DOING STABLE CHORES

PLACE: Sunrise Equestrian Centre, near Guelph Lake.

TIME: Fridays at 3:15 for 3/4 hour, during the winter months.

WORK: Feeding and caring for 15 horses at the stable.

MODE OF TRANSPORT: transported by car by sister (15 mins).

FOLLOWS PREVIOUS ACTIVITIES: prior to going to Sunrise, Andrew has a 1.6 kilometre walk around the block, in order to:

1. reacquaint him with his home neighbourhood after a week away; and
2. take responsibility for leading and looking after his dog, Zach.

MOTIVATION/WEEKLY STIMULATION:

Before going to Sunrise for the work, Andrew needed discussion about what he was going to do there and the sequence of steps:

1. Using FC on his Epson computer, Andrew talked about how his week had been, how he felt, and the sorts of activities he was looking forward to at home that weekend. Going to work at Sunrise was always a motivator for him for two reasons; a) because he would see friends like Marla there who would talk to him about bowling and other significant events in his life, and b) because he enjoys taking care of horses.
2. During the walk and in the car, his sister would discuss with him the plan for the afternoon, reminding him of the general steps involved in the work, so that by the time he got to Sunrise, he remembered the procedures. Also, it was important, to talk about the black dog, Misty, and to remind him that she might suddenly appear and how he could deal with this potentially difficult situation. Andrew finds both these advance methods of discussion useful.

PRECISE WORK TASKS AND STEPS INVOLVED:

1. Upon arrival to Sunrise, Andrew and his sister would go and locate Marla (the horsewoman) in one of the barns and learn what work was needed.
2. Usually the first job was to feed the horses.

STAGES INVOLVED IN THIS TASK:

- a. The first part involved going to the feed room and filling one plastic container with grain/molasses mixture, and a smaller container with bran.

- b. Andrew then filled each horse's black feeding tub with the grain/molasses mixture; and for the ponies giving them a handful of bran mixed in with this. Amounts of feed varied for each horse, and were posted on the stalls. Andrew's sister read these amounts aloud, and he carefully measured them out. He then placed the black feeding tubs in each stall ready for the horses, and returned the containers of bran and grain/molasses to the feed room.
 - c. After all the tubs were full, Andrew sometimes assisted bringing in bales of hay. These were then broken down into small sections and a strand was placed in each horse's stall.
 - d. Andrew also filled up containers of water for the horses to drink - some were outdoors and others indoors.
 - e. Andrew then stood in the tack room, while some horses were let out of the fields and ran into the stables. His job was then to lock each horse and pony into its stall so that would not run loose or steal other horse's food. (Sometimes he was a bit slow latching them in and Sir William particularly would steal others' grain).
 - f. Andrew would assist in bringing some horses in from the fields. Marla would give him a lead rope and help him attach it to the horse and show him how to lead the horse carefully into the right stall. It was important to lead the horse on the right hand side.
 - g. After all the horses had eaten, Andrew removed the black tubs from each stall, placing them either on a hook on the door or on the floor outside. He would then, with prompting, let some of the horses back out into the fields.
3. Andrew would then assist with sweeping the large barn. He would go to the other barn and find the push broom (which he found easier to use) and then take it back to the other barn. He then carefully swept hay and other debris into an empty stall.
 4. After this, Andrew and his sister would then talk with Marla about the plans for the next week - checking that there would be work and what time to come. They also chatted briefly about important events in Andrew's life, such as other work and recreational activities.

AFTER THE WORK: Andrew was motivated by the thought of a cup of tea and snack (fruit or cookie) after work.

DEBRIEFING: Andrew likes to talk on his Epson after the activity about how it went - what he enjoyed, how it felt etc. It was important for his sister to be reinforcing and positive at all stages of the work, especially if Andrew was slow. (This was sometimes challenging with frozen feet!)

DELIVERING SEARS CATALOGUES (July 1995-February 1996)

PLACE: Neighbourhood in Kitchener (River/Ottawa/Manchester area); also continued in several Guelph neighbourhoods.

TIME: Some Sunday mornings from 10-12.

WORK: Labelling and delivering catalogues to c.70 homes.

MODE OF TRANSPORT: transported by car by his sister.

FOLLOWS PREVIOUS ACTIVITIES: before the drive to Kitchener, Andrew has a 1.6 kilometre walk around the block, in order to:

1. reacquaint him with his home neighbourhood after a week away; and
2. take responsibility for leading and looking after his dog, Zach.

MOTIVATION/WEEKLY STIMULATION:

Before going to Kitchener for the work, Andrew needs discussion of the purpose and sequence of steps will be, in takes two forms:

1. Using FC and his Epson computer, Andrew talks about he feels; the sorts of activities he is looking forward to doing at home that weekend. Going to work in Kitchener is a motivator for him for two reasons; a) because he likes work in the fresh air; and b) because it is followed by bowling.
2. On the way to Kitchener (25 minute trip), his sister discusses with him the plan for the morning, reminding him of the general steps and detailed procedures. Also, it is often important to talk about possible encounters with dogs in the community. Andrew find both these advance methods of discussion useful in that he is well briefed for work.

PRECISE WORK TASKS AND STEPS INVOLVED: IN ADVANCE

1. Prior to delivering the catalogues to the houses, the address labels need to be put in geographical order for the most efficient delivery. Andrew can do a lot of this, with some assistance.
2. The address labels then need to be affixed to the catalogues with sellotape. Andrew does this totally independently.

STAGES INVOLVED AT WORK SITE

Upon arrival to the neighbourhood, Andrew and his sister deliver catalogues to c. 70 addresses (one house receives two catalogues).

The catalogues are placed either:

- a) in the mailbox
- b) between the doors, or
- c) given to an individual at the house

Andrew can deliver these very independently to each house (One thing is to watch that he does not tidy up other people's yards too much!)

AFTER THE WORK: Andrew is motivated by the thought of bowling in Guelph after the work.

DEBRIEFING: Andrew likes to talk on his Epson computer after the activity about how it went - what he enjoyed, how it felt etc.

In the transition year of 1996 and since Andrew has lived full-time in Guelph from January 1997, Elizabeth and Gerry have tried to find opportunities for Andrew to work at home and in the community. He cleaned and helped with various chores in two churches, and he has increased the number of organizations for which he does collating. At home, he already knew how to do laundry and dishes and set and clear tables. He learned to plan meals, to cook and bake, and from July 1996 began to prepare breakfast for his dad and himself each morning he was home. Gerry was served his tea, toast, cereal and juice on a tray in bed! Gerry developed a new work activity for Saturdays from July 1996—using saws and shears to trimming the lower branches from pine and spruce trees in a friend's farm plantation.

Other new skills have been learned since Andrew has lived in his own house and has the support of a full-time tutor. Andrew's present tutor Teresa has supported him for 15 months (full-time for 12 months). She has provided the regular, patient training and practice he needs to learn new skills. Outstanding successes of this time are his computer work (described in chapter 7), and the new skill of working with metal, using a hand-press to fold strips of sheet-metal into brackets at the Ensings' heating and air conditioning shop. Andrew's first introduction to this work in September 1997 was not promising, and his support team might well have decided that it was not for him. It took four visits, and unflagging patience and positive thinking by Gerry, Teresa and Elizabeth, to turn the situation around into positive attitudes and achievements.

WORK AT ENSING HEATING AND AIR CONDITIONING

Since 3 September 1997, I have had a job in the shop of a good friend, Mr Ensing, who owns a business installing heating and air conditioning units in peoples' homes. For each of these unique units to be fitted, they need what are called "cleats", which are small folded strips of metal (approximately 8 and 10 inches) that form corners. It is my job to take cut metal strips and fold and press then into cleats using a hand-powered press. When I was first introduced to the folding apparatus, I felt apprehensive and concerned about co-ordinating the lever so as not to injure my hands. However, with practice and reassurance from my parents and tutors, I overcame this hesitation and have mastered the task using only one hand!

I have worked once or twice a week for 14 months now. My best output is pressing up to 135 cleats in 80 minutes. Mr Ensing says he is pleased with the quality, and pays me well. I enjoy this job as I have the luxury of a quiet work setting and I am able to work independently and efficiently.

Andrew does most of his collating at his home, where it is fitted around the edges of his other work and learning time with Teresa. It is helpful to have some such work on the go at all times. When, as usual, the organization wants the job done quickly ("yesterday"!), Andrew's family will join him to meet the deadline. His biggest assignment to date was also the most complex, for the Faculty of Environmental Studies at the University of Guelph. It involved sorting and inserting materials into some 5,000 envelopes of six different types, which were then further organized into 840 mailings to all high schools in Ontario. Twice a year, early in each fall and winter semester, Andrew fulfils a paid collating assignment onsite, in the University of Guelph's Human Resources Department. Supported by Teresa, he sticks labels on 3,000 booklets, one for each of the

University's full-time employees, and then bundles the booklets by departments. This opportunity was the bright idea of his good friend Marg Middleton.

Andrew does most of his work as a volunteer, for organizations and causes that seem worthwhile. The purposes and value of his work are discussed, and he may type summaries and social stories. Some people and groups for whom he works have given him gift certificates so he can choose books, music or computer CDs. As well as his collating, he has volunteered for Sunrise Equestrian, the Donkey Sanctuary of Canada, the Ignatius Farm Community, and the City of Guelph Recreation and Parks Department (by picking up litter and debris in Riverside Park East once a week). To encourage opportunities for more work, Andrew has composed and typed his resume, and written stories about several of his work experiences.

DONKEY SANCTUARY REPORT

On November 29th 1997 Teresa and I paid our first visit to the Donkey Sanctuary of Canada. This new volunteer venture was inspired by my interest in and ability of feeding and grooming horses at Sunrise after lessons. At the Sanctuary we met with Karen Hunsberger, the animals' primary caretaker. She explained that the donkeys, goats and mules were retired and that there are approximately 30 donkeys on the 200-acre property. We also learned that it would be most helpful to groom the animals, and that Friday afternoons are a good time to come.

The first time we volunteered was Friday December 19th and this time we met Meri-oui. She was sweeping the barn and had a very friendly manner. She was a former employee and knew quite a bit about the donkeys' histories and personalities. We learned a few of the donkeys' names, which are often striking and reflect each donkey's character. It didn't take long before some of the donkeys came close to us because they quite enjoy being groomed. The ones in the pasture all looked to us as if saying farewell when we headed back to the car - what a lovely gesture!

ANDREW BLOOMFIELD'S RESUME (TO LATE 1998)

23 Waverly Drive, Guelph, Ontario, N1E 1G6, phone (519) 823-9323

Objective: To learn new skills, and use established skills in a variety of work settings

Skills:

Adept with numbers, patterns and hand-eye co-ordination

Adept at office skills such as photocopying and collating

Experienced with computer and library work

Experienced with manual work i.e., cleaning, painting, digging and raking

WORK EXPERIENCE

1. OFFICE SKILLS, 1985 -Present

Collating newsletters and booklets, stuff envelopes, stamp and affix labels for mail distribution; and photocopying or copy-typing for the following:

Autism Society Ontario (Wellington); Waterloo-Wellington Autism Services; Guelph Services for the Autistic; University of Guelph (various units); Waterloo Historical Society, Credit Valley Conservation Authority; and Guelph Historical Society; Bridges

2. RECYCLING, STOCK HANDLING AND ORGANIZATION, 1988 - 1997

Sorting materials for Sarnia recycling depot (1990)

Recycling cardboard boxes for Listowel Co-op (1994-6)

Stocking and arranging shelf products of supermarkets and other stores in Maple (1988-9), Petrolia (1990) and Guelph (1997)

3. LIBRARY SHELVING, 1988-1995

Shelving books in one library with Dewey Decimal system and another library with unique system

4. STABLE CHORES, 1992 - Present

Grooming and feeding horses after riding lesson at Sunrise Equestrian Centre; grooming donkeys at The Donkey Sanctuary of Canada

5. CLEANING AND HOUSEHOLD CHORES, 1994 - Present

Cleaning floors, tables, benches and bathrooms of the Bullring (campus pub) at University of Guelph - two hours per week in fall 1994

Vacuuming at a motor hotel in Palmerston and two churches in Guelph (also painting and stonemason work at one church)

6. TREE PRUNING AND LANDSCAPING, July 1996 - Present

Pruning trees for sustenance of forest environment at Spirit Valley Farm.

Raking leaves and mulch, digging and planting gardens and maintaining lawns of private owners

Clearing litter and debris in public park (Riverside Park East) for City of Guelph Recreation and Parks Department

7. STEEL PLATE FOLDING, September 1997 – Present

Ensing Heating and Air Conditioning Ltd

8. COMPUTER PRODUCTION OF PICTURE COMMUNICATION SYMBOLS using Boardmaker software, 1998 -

10 *A HOME OF MY OWN*

Most of his life, it has seemed that Andrew thought of himself “in the third person,” avoiding pronouns like “I”, “me”, and “mine.” Living in his own house has given him more sense of himself. He walks tall, with the pride and sense of responsibility of an owner. So using the “first person” in the title of this chapter (and in the book title) is deliberate. The house is the core and base of Andrew’s person-centred plan, and the symbol of his rights and powers of choice.

The three-level house is spacious, situated in a fine Guelph neighbourhood, close to open parkland along the River Speed. Mature trees offer shade to the lot and driveway that has space for six cars; there is also a double garage. Andrew has his red bedroom and large green “relaxation” room on the main floor, with the eat-in kitchen, large living room and four-piece bath that can be shared by the whole household and by members of Andrew’s support team and visitors. On the east side is an addition to the original house, consisting of a private wing with three large bedrooms and a four-piece bath, above the garage. Downstairs, a legal apartment of 450 sq. ft. has been created on the sunny south side of the house, and there are also a large room for hobbies and special projects, and a utility room with full laundry facilities. This is Andrew’s own house, to be shared with friends of his choice.

Some people might think that such a house is too generous for one person—especially someone with disabilities. But there are sound reasons for Andrew to have this house as his own.

1. He needs to have living space that is roomy, cool, quiet and designed to help him cope with his extreme sensitivities to noise, touch, crowds, some foods, drugs, and to temperature and weather changes.
2. He needs space inside the house to be a base for his structured timetable of real work, continued learning and exercise. This is where he works on the computer, does most collating, and also learns and practises the skills of food preparation and caring for his house. This is home from which he and his tutor or other friends go out into the community for other forms of work, learning or exercise.
3. He needs a place where he can relax and which his friends can visit to enjoy shared interests. His calm green relaxation room holds a Bell piano made in Guelph in 1864 (and on longterm loan from one friend). There are special lights, a large terrarium, and CD equipment that plays classical music almost all the time. His house has a growing collection of indoor plants. In the downstairs recreation room with a fireplace, a friend has built the framework for a model railway and there is space for other special projects.
4. He needs a sense of space around his house. His garden is being developed as a healing naturescape, replacing the former deep swimming pool and boring lawn

with native and naturalized plants, a pond, aromatic and culinary herbs, organic vegetables, and a greenhouse to extend the growing season. As in the house, Andrew is involved in all the work of improving and maintaining his garden.

5. He needs a sense of green open space in his neighbourhood too. The environs of Andrew's House could hardly be better. It is only eight houses up from Guelph's Riverside Park, with all its formal and informal open space and many trails. Across the road, a large golf course established before the First World War provides an attractive vista. Andrew's neighbourhood is ideal for the regular walks with Zachary and friends. He is learning to move around more independently, preparing for the opportunities that his future guide dog will give him. Within easy walking distance are two shopping centres, and he will be able to catch a Guelph Transit bus 200 metres from his front door.

6. He needs, at least for some years, to be *the* focus person in his house, to make up for long years of trying to share intimate space and the attention of carers with others who could speak up, even clamour, for their demands. His multi-modal communications, special diet, and the relaxing strategies that provide alternatives to punishing and toxic drugs must be maintained by support people who are not too distracted.

7. He needs a real assurance of permanence to carry on from the 29 years that his parents' house has been his home (though his life was too long divided between home and other places). By endowing his house now, his parents help him to make the adjustment to a life of his own, while they still have resources and resilience to make this possible. His new life must be set up for success and the long term, recognizing that he needs time to get used to a new environment and new people. If there are any problems in future, he will not be the person who moves out.

8. He needs the companionship and emotional and physical support of *several* people, preferably in more natural social relationships than only as paid staff. Their role is to train and support Andrew to look after himself, his dog and his house, rather than to do these tasks for him, and to give him emotional and physical companionship and a sense of shared interests. These roles are both too demanding and potentially boring for only one or two people—leading to burnout and/or carelessness. Many examples might be given of the benefits of a larger household. On the other hand, a single carer is too isolated and risks losing patience. Andrew also needs the stimulation of conversation and other people's interests around him. Maintaining this alone is impossible. A household community is planned, in which several people will co-operate to support Andrew's occupancy while continuing their own studies or jobs and enjoying the fellowship of the shared household.

Homesharing has become Andrew's own choice for the future. Since he moved into his own house at the end of July 1997, his mother and dog have been his first "homesharers" until the way opens for others to join him. His house,

originally bought in trust by the Bloomfields, now belongs to the non-profit charitable corporation, Guelph Services for the Autistic (GSA), which is committed to supporting Andrew's lifelong occupancy. As Andrew has high needs in getting used to living in the community, he has a sole tenancy agreement with GSA. GSA is now responsible for meeting mortgage payments on about 40 per cent of the value of Andrew's House, Andrew paying the whole of the shelter portion of his disability pension (ODSP) to GSA as rent. The remaining costs of purchase, renovations and equipment have been borne by the Bloomfields.

In Andrew's House, up to five homesharers will trade their personal commitment in return for reduced-cost accommodation. They will contribute to the operating costs of the household (including utilities) but are not legal tenants and do not receive wages or stipends. For an average nine hours a day, Andrew will have individual support staff, so that homesharers are free to earn their living and/or pursue studies. The right homesharers are selected by and receive training and moral support from Andrew's Support Cluster of friends (of which a core group, Andrew's House Committee, is a legal committee of GSA).

The invitation to prospective homesharers describes a *"new intentional community in Guelph that is inclusive, co-operative, humanitarian, and ecologically and ethically responsible. It could suit undergraduate and graduate students who have a sense of commitment to the disadvantaged and community well-being, and who may want to test their ability to work in more challenging fields of human service, such as CUSO or L'Arche, or in religious ministries. This experience offers you:*

- *The life credits of sharing in a supportive household around a person who has special challenges but also the great advantage of a house of his own and a remarkable cluster of friends. Andrew's House is a flagship of a new model of community living that is being watched with interest.*
- *Training, participant observation and experience in a range of effective strategies—including cognitive and multimodal communication methods, alternative diet and freedom from drugs, relaxation, horticultural and pet therapy—which add up to a way of life that is designed to be seamless for Andrew.*
- *A kind of practicum for a range of applied sciences—including language development, psychology, family studies, human nutrition, kinesiology and ecology.*
- *The bonus of living rent-free in a spacious house and garden in a mature neighbourhood (while contributing to the cost of utilities, groceries and household maintenance).*
- *Specified roles and responsibilities, allowing quite enough time to pursue full-time studies or to hold a full-time job.*

As a homesharer, you will not be caring for Andrew so much as encouraging him to do things for himself, as well as providing emotional support and companionship, and ways for him to connect with the larger community."

Andrew's plan, including his rights to live for as long as he wants in his own house, has attracted wider interest and support. Andrew, his parents and friends want to make the right decisions--for his sake, and also for all the other vulnerable people whose life plans could benefit from similar approaches and ideas.

What has it been like for Andrew to live in his own house? Being the only disabled person he escapes the distress, distraction and compromise that he had in the close quarters with other disabilities in institutions. He has support and companionship that is compatible with his particular needs. He copes so much better in behaviour and develops skills faster in a home environment where he has structure and predictable routines around his needs and capabilities, something a group home with its relays of staff serving several challenging individuals, could not give him. The spacious layout of his house and garden already has proved ideal for his needs for quiet and green space and varied forms of exercise and "real" work. As friends drop in for games, music and recreation and his circles of friendships increase in the community, Andrew gains in his social relationships. He is a happy man.

The house on Waverly Drive is Andrew's base where he is learning and practising household skills: cooking, cleaning, laundry, gardening. It is the place that gives Andrew rights and powers of choice. He can choose what the menu will be for supper or whether or not today he will plant sunflower seeds in his garden. He can choose his friends. He can select which activity he will plan for the morning. Life is full, a fulfilment of his own decisions. The homesharing model of living with residential support has benefited Andrew's personal growth with gains in self-esteem. Andrew stands tall.

Using FC Andrew has said: "AB wants to try best to be a good man." The meaning of life is, he says, "To help people. To love others." He says he often dreams in the colour green (his favourite colour). In his dreams he is in a happy, beautiful place with Vickie, and he has no autism.